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Voluntary Health Sector Working Papers 2002

(Volume 1)

Health Canada
April 2002

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Également disponible en français sous le titre
Secteur bénévole de la santé - Documents du travail 2002

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Catalogue: H39-613/2002-1E
ISBN: 0-662-31985-0

Voluntary Health Sector Working Papers 2002

(Volume 1)

Voluntary Sector and Strategic Frameworks Unit
Population and Public Health Branch
Health Canada

April 2002

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Foreword

Canadians rely on and believe in the voluntary health sector. Voluntary health organizations build on the contributions of time and money of millions of Canadians to provide services in our communities, carry out research, advocate for improvement and raise funds, all in order to improve the well-being of Canadians across every population group and against every risk to health. They also build community capacity by involving Canadians as volunteers.

A majority of Health Canada's policy and program partners are voluntary organizations, and a substantial proportion of departmental expenditures is invested in the voluntary sector. While we know about the effectiveness of individual programs and organizations, there is little quantitative or qualitative evidence about the voluntary health sector itself. Because it is a key partner, we want to advance our understanding of this important sub-sector of what the Prime Minister has called the 'third pillar' of society.

The important contribution of the voluntary sector to the health of Canadians highlights the need for a comprehensive body of research on its role and impact in Canadian communities. Recognizing this, the Voluntary Sector and Strategic Frameworks Unit, Population and Public Health Branch commissioned a number of research papers. *Voluntary Health Sector Working Papers 2002* brings the papers together as a contribution to the understanding of the unique knowledge, perspective and expertise of Canada's voluntary health sector and its important place in Canadian life. The papers address knowledge gaps in government, academia and policy circles in Canada and internationally.

Volume 1 of *Voluntary Health Sector Working Papers 2002* consists of six papers on various aspects of the voluntary health sector, while the four papers in Volume 2 have as a common theme the results of the National Survey of Giving, Volunteering and Participating. The authors of these papers form a diverse group - community health workers, economists, policy experts, quantitative researchers, academics, and staff of Canadian voluntary sector organizations - and their work covers a broad range of topics.

The publication of these working papers also complements other current Health Canada and federal government initiatives to improve the delivery of health services to Canadians and to strengthen partnerships with the voluntary sector.

Health Canada would like to thank the authors of these papers and the organizations with which they are affiliated for their generous contribution to increasing our understanding of the vital part the voluntary health sector plays in maintaining and improving the health of Canadians. Thanks also go to Mary Jane Lipkin, Manager of the Voluntary Sector and Strategic Framework Unit and Karen Hill, Senior Analyst for bringing these papers to publication.

Amanda Cliff
Director General, Strategic Policy Directorate
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Introduction

An Important Contributor to Health and to Society

Sometimes the contribution of Canada's voluntary health sector is highly visible, as underlined by the role of the Canadian Red Cross in post-September 11 emergency efforts in both Canada and the United States. At other times the contribution is as quiet and understated as the hospital volunteer who brings a warm blanket to someone who has just had surgery.

But whether the people and organizations that make up this sector are working in the spotlight or behind the scenes, the Voluntary Health Sector (VHS) in Canada is a huge contributor to the health of Canadians. And Canadians trust and believe in the VHS - each year, more than half of us donate to health charities, and the health sector receives the largest proportion of charitable donations made in all sectors.

However, despite being a major contributor to the health of Canadians, the VHS is poorly understood.

Understanding the Sector

We know the VHS is a major contributor to health research and generates many millions of dollars annually for research funding. However, very little focused research has been done on its role, size and composition. Unlike the funded health sector, we as yet have no comprehensive map of the voluntary health sector. As a consequence, the real role of the VHS in the health system has been largely unknown and undervalued.

First, what is the VHS? To put it simply, the VHS consists of organizations and volunteers that devote their efforts to improving human health. This is done in many ways – advocating health concerns, service delivery, research, public education, policy development and fundraising are just a few of them.

The Working Papers

As part of the federal Voluntary Sector Initiative, and in keeping with its commitment to knowledge development and research, Health Canada has published these working papers in *Voluntary Health Sector Working Papers 2002 (Volume 1* and *Volume 2)*. Each paper in these collections contributes to the beginnings of a body of knowledge about the role and responsibilities of the voluntary sector in health in Canada. As such they will help build interest in the development of a research agenda about and for the voluntary sector in health; they will inform policy and program development in the public and voluntary sectors; and, it is hoped, spark further research efforts into this important sector.

About the Authors

Judy Birdsell is the principal consultant with On Management Limited in Calgary, Alberta. Her areas of focus include organizational analysis and strategy in the health, nonprofit and health research domains, with particular interest in interorganizational relationships, organizational performance and research utilization. She also has a 20-year history of volunteer involvement in the health nonprofit sector, including roles as chair of the Boards of the Canadian Cancer Society, the Canadian Breast Cancer Research Initiative, and the Stem Cell Network. Judy has a B.Sc. degree in Nursing, a M.Sc. in Health Care Research and a Ph.D. in Organizational Analysis.

The primary research interests of **Arslan Dorman** are international political economy and Canadian public policy. Arslan has been an associate of the Centre for Voluntary Sector Research and Development at Carleton University since 2001 and has done research on the voluntary sector for the Centre.

Jill Finley is a graduate student in the Faculty of Management at the University of Lethbridge in Alberta. Jill is a graduate of the Bachelor of Commerce program at McGill University. Prior to commencing graduate studies, Jill worked for several years in the energy sector in Ontario and the north. She understands community relations through her work as a volunteer and as a professional. Recently, Jill and a group of concerned citizens in Inuvik formed the Inuvik Recycling Society to raise public awareness and affect positive social change.

Femida Handy, Ph.D, teaches economics at the Faculty of Environmental Studies at York University in Toronto. Her award-winning research on the nonprofit sector has been published in many leading journals and various other practitioner-oriented publications. Her area of interest includes a variety of issues related to the nonprofit sector: volunteers, fundraising, entrepreneurship, wages, advocacy and issues of trust and reputation.

Since 1999, **Karen Hill** has worked as a Senior Analyst in the Voluntary Sector and Strategic Frameworks Unit, Population and Public Health Branch, Health Canada. Prior to this, Karen worked in several federal departments, building on 20 years of professional experience in voluntary sector social planning organizations. She also brings to her work substantial volunteer leadership experience in both Canada and the United States, and has published numerous articles about issues of interest in the voluntary sector.

Marguarite Keeley has been the Executive Director of Centretown Community Health Centre in Ottawa since January 2000. Prior to that, she was a senior manager in Health Canada's Medical Services Branch, and was responsible for the early development and implementation of the transfer of control of community health services to First Nations. Before coming to Ottawa to complete a Master's degree in Public Administration, Marguarite worked in community recreation in North York, followed by six years as a community coordinator for the Etobicoke Social Planning Council.

Christine Smith has been a community volunteer for the past 15 years. Christine has been involved with the Canadian Breast Cancer Foundation since 1989. She served as Chairperson of both the Ontario Chapter and National Board of the Canadian Breast Cancer Foundation from 1996-1998. She lives in the Toronto area with her husband and two children.

B.E. (Bernie) Williams, Ph.D., is an Assistant Professor of Organizational Studies in the Faculty of Management at the University of Lethbridge in Alberta. He has conducted research on voluntary sport organizations and both voluntary and career fire and emergency medical services organizations. His current research interest is the exploration of alternative organizational models for the delivery of health care and health related services.

Elinor Wilson, Ph.D., is currently Chief Science Officer at the Heart and Stroke Foundation of Canada. She is also the Co-Chair of the Conference of Principal Investigators of the Canadian Heart Health Initiative, a member of the International Dissemination Committee for the Victoria Declaration, a member of the Ministerial Advisory Committee on Tobacco Control, Chair of the Framework Convention Alliance, President of the InterAmerican Heart Foundation and Vice-President Elect of the World Heart Foundation. Elinor has a R.N. degree and a Bachelor of Arts degree from the University of Manitoba, a Master's degree in Health Sciences from McMaster University, and a Ph.D. from Walden University in Minnesota.

Executive Summary

The six papers in Volume 1 of *Voluntary Health Sector Working Papers 2002* look at a variety of important aspects of the voluntary health sector in Canada from the unique perspectives of a diverse group of authors. As their short biographies indicate, these authors bring a richness of experience to this work.

The first paper in this Volume 1 collection is "The Voluntary Health Sector: Successful Advocates for Health Research Funding" by **Elinor Wilson**, Chief Sciences Officer with the Heart and Stroke Foundation of Canada. This paper highlights the recent successful advocacy role played by health charities in Canada.

Despite efforts by government and the voluntary sector, during the 1990s Canada was significantly underfunding health research in comparison to other countries. The government responded to the voluntary health sector's advocacy efforts on this front through the setting up of a task force which proposed a new model for organizing and funding health research. The result was the establishment of the Canadian Institutes for Health Research across the country.

After presenting some background theory on advocacy and demonstrating how Canada's health research expenditures were lagging behind in the late 1990s, Wilson's paper tells the story of how advocacy was used by health charities to achieve real results for the benefit of Canadians. In particular, the roles of the Health Charities Council of Canada and the Council for Health Research in Canada are described. The paper concludes with issues and questions for further study.

By demonstrating the voluntary health sector's success in advocating for improved funding for health research, Wilson's paper highlights one of many important roles played by the voluntary sector in general and the voluntary health sector in particular.

In the second paper in this collection, "The Voluntary Health Sector: Integrators across Health Domains" authors **Marguarite Keeley** and **Karen Hill** examine how voluntary community health centres (CHCs) act to bridge and connect patients, communities as a whole, practitioners, educators and policy makers around health issues.

Their paper summarizes policy directions, defines and describes health and current health issues, and provides responses to a number of important questions – for example, what is the relevance for primary health care reform of the CHC model of organizations that provide primary health care services but are also volunteer-driven, multidisciplinary, accountable to the community, and focussed on prevention and health promotion?

Keeley and Hill describe the activities and structures of a number of CHCs in eastern Ontario. The authors conclude that although the role of the VHS in Canada's publicly funded and publicly administered health system has not been articulated, the CHC model appears to

meet many objectives of health care reform. CHCs provide comprehensive services across many sectors of society and help build stronger communities.

Their paper concludes with recommendations for further research. Suggested activities include, for example, an examination of the relevance of the CHC model to other jurisdictions and an investigation of the impact of the CHC model on the health of populations.

Next in this volume is **Judy Birdsell**'s "Understanding the Role and Contributions of the Voluntary Health Sector Within the Health System: An Organizational Focus". Her paper discusses what needs to be done to understand the role and contribution of the VHS in service delivery across the spectrum of health services - from health promotion and wellness to palliative care. Her examination of the nature and range of organizational relationships through which the VHS interacts with and influences the formal health system is also a contribution to the emerging picture of the VHS being drawn by other Canadian researchers.

Birdsell's research involved two components: a literature search and a content analysis of annual reports of selected national health charities. She identifies a number of general roles of the VHS; as well, she lists and describes dimensions that need to be further researched in the development of a comprehensive conceptual framework to shape and interpret research on the VHS. These dimensions include, for example: the extent of formal organization of volunteer efforts; a clear articulation of the differentiation between public, private and voluntary sectors; and, outcomes and outputs resulting from interactions between voluntary health organizations and the formal health sector. Some policy questions that could be addressed by having improved knowledge of actions and impacts of voluntary health organizations include, for example: What may be the potential impact of government grants? What models of interaction between the voluntary health system and the formal health system translate into improved health or improvements in health services delivery?

Her study also includes an annotated bibliography and several "Canadian Vignettes" describing a sampling of VHS activities in Canada.

In "An Inventory of Voluntary Organizations Providing Health and Health-Related Services in Two Alberta Communities" authors **B.E.Williams** and **Jill Finley** provide preliminary insights into the scope and breadth of the voluntary health sector in Canada. They do this through an examination of the voluntary organizations that provide health and health-related services in two communities in southern Alberta – one urban community (Lethbridge, population 70,000) and one rural community (Taber, population 7,000).

The authors discuss criteria and methods for classifying voluntary health organizations and then describe how they set out to compile an inventory of these organizations which would, in turn, allow them to do a comparative analysis of services offered in these two communities. Williams and Finley developed a questionnaire and identified respondents. Sixty organizations were identified – 46 based in Lethbridge and 14 based in Taber. They

were successful in completing interviews and questionnaires with 31 organizations in Lethbridge and 9 in Taber for an overall response rate of 67 percent.

The basic criteria for comparison were developed around the basis for organizing, types of services, types of service delivery, internal processes and governance, and methods of securing resources. Overall, there was no unique or discernible pattern in the results that would allow the authors to conclude that the two communities were fundamentally different in the types of organizations that exist and in the types of services these organizations provide. The research suggested that the majority of organizations are driven by demand or need for services.

The authors suggest that further similar research should be done in other geographic centres and regions, as well as on the informal provision of services – by family and friends, for example – which was beyond the scope of the current study.

Breast cancer is a serious health concern for women in Canada - one in nine Canadian women will develop breast cancer, and many of those who do not develop this cancer will still share in the experiences of family members or friends who do. The next study in this collection, by York University professor **Femida Handy** and **Christine Smith** of the Canadian Breast Cancer Foundation, uses a scan of Toronto-area voluntary health sector organizations associated with breast cancer to offers a framework to assess the impact of VHS organizations.

In "From Discovery to Recovery and Beyond: The Voluntary Health Sector's Response to Breast Cancer" the authors use a fictional composite character to present, in narrative form, the results of their investigation into how women with breast cancer choose to interact with VHS organizations.

One of their findings is a marked lack of the individuals' involvement with VHS organizations during the time between diagnosis and surgery.

Handy and Smith explain how VHS organizations work at both the micro and the macro level. At the micro level, these organizations have an impact on women diagnosed with breast cancer and on their families, as well as on women seeking information about breast cancer. At the macro level, VHS organizations work in advocacy, and also do research on prevention, screening, treatment and a cure.

The authors conclude that while the diversity of VHS organizations give this sector its strength, this diversity also makes it difficult to measure the real impact of these organizations.

Nevertheless, Handy and Smith propose four proxy measures of impact - the supply of services and their distribution by region, the demand for services across regions, comparisons of incidence and mortality across regions, and the impact of government spending compared to VHS spending.

A comprehensive listing of VHS organizations regarding breast cancer in the Toronto area is provided in an appendix.

In the final paper in this volume, "An Inventory of Past Research on the Voluntary Health Sector in Canada", **Arslan Dorman** presents the results of a quantitative search of published research findings on the voluntary health sector.

By using a broad definition of the voluntary health sector and a generous time frame, and by classifying his results into publication categories - journals, books, conference materials, dissertations and theses, as well as newspapers and magazines - Dorman sheds light on publishing trends. Not surprisingly, much of the in-depth research on the voluntary health sector in Canada has been published in academic journals.

Dorman's subject/topic analysis found that over half the published voluntary health sector research is of a general nature, while more than a third consists of organizational case studies. Studies on specific issues such as health promotion or education, for example, form a very small percentage of total published research. Dorman's report also includes a list of journals where voluntary health sector research is most frequently published - *Social Science and Medicine* and the *Canadian Journal of Public Health* top the list - and a listing of the main social science and science indexes used in his research.

This look at who is publishing what in which publications points to the gaps in voluntary health sector research, an essential step in providing workable proposals for remedying this situation. Dorman concludes his paper with recommendations for creating and sustaining academic interest in voluntary health sector research.

Dorman's paper includes a 150-entry inventory of published voluntary health sector-related research, a useful resource for other researchers studying the voluntary health sector in Canada.

Together, these six papers make up *Voluntary Health Sector Working Papers 2002 (Volume1).*

The Voluntary Health Sector: Successful Advocates for Health Research Funding

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The opinions expressed in this paper reflect the views of the author and do not necessarily reflect those of the Heart and Stroke Foundation of Canada.

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The Voluntary Health Sector: Successful Advocates for Health Research Funding

Introduction

The voluntary sector in Canada is extremely diverse. While we have very limited information about the sector, it is estimated to consist of some 175,000 organizations, slightly over 78,000 of which are registered charities.[1] These organizations vary considerably in size, budget, purpose, structure, approaches and funding sources. In addition, these organizations range across a host of areas, including social and community services, international activities, education and health, arts and culture, sports, religion, community and public foundations, and environment. While some organizations have multi-million dollar budgets, elaborate and sophisticated board structures, trained staff including paid professionals and an extensive network of volunteers, others have little or no budget at all and rely entirely on a handful of volunteers and past contributions from members and neighbors.[2]

As the diversity in its composition, size and activity areas suggests, the voluntary sector fulfills many different functions: representation of groups and individuals who otherwise might not be heard by government; delivery of services not delivered by the government sector; and, citizen engagement – a way for citizens to connect at a community level and work together for overarching goals.

The role of the voluntary sector can be categorized as being complementary, supplementary or adversarial.[3] This is dependent on what it is that the sector is attempting to accomplish at any given time. The adversarial role, or stated positively the advocacy role, is a well-known activity of the voluntary sector, and it is this advocacy role that is examined in this paper.

More specifically, this paper looks at a recent example of the vital advocacy role played by the charities that fund health research in Canada to help increase government funding to this health research. The paper focuses on the role of two organizations in particular, the Health Charities Council of Canada (HCCC) and the Council for Health Research in Canada (CHRC).

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[1] Hall M. and Banting K. "The Non-Profit Sector in Canada: An Introduction." Kingston School of Political Studies: Queen's University, 2000. Available online at http://policy.queensu.ca/sps/ThirdSector/Papers/Hall-Banting/TheNonprofitSectorInCanada.html.

[2] Good, D.A. "A Government Voluntary Sector Accord." ISUMA *Canadian Journal of Policy Research* 2001;2(2):46-52.

[3] Steuerle, C. Eugene and Hodgkinson, Virginia, "Meeting Social Needs: Comparing the Resources of the Independent Sector and Government," Section II, Chapter 2. In Elizabeth T. Boris and C. Eugene Steuerle (eds.), *Non-Profits & Government: Collaboration and Conflict,* Washington, D.C.: The Urban Institute Press, 1998. Check online at www.urban.org/pubs/npag/contents.html.

After presenting some background theory on advocacy, and briefly demonstrating how Canada's health research expenditures were lagging behind in the late 1990s, this paper tells a story – the story of how advocacy was used by health charities to achieve real results for the benefit of all Canadians.

Advocacy – Some Theoretical Perspectives

Throughout history, as civilizations and countries evolve, distinct groupings occur. A definition emerging in recent years of a "civil" society is this: for a country to be functioning at its highest level, a complex and delicate interaction among government, the non-governmental sector and private sector must occur. This balance must not only occur, but also must also be valued and enhanced.

The voluntary sector, then, can be seen as one of three pillars of civil society. These three pillars are the public sector, the private sector and the voluntary sector. However, the interrelationships among these three pillars – the specific details of what these relationships are and what they should be – are the subject of debate.

In the United States, the debate about non-profits' role in advocacy is intense. And although the laws and contexts are different in Canada, it is useful to look briefly at American theory on advocacy because of the scrutiny it has been given.

Various theories on the role of groups in public life in America have been espoused, with corresponding theories on advocacy. Some analyses make distinctions between society-focused advocacy and government-focused advocacy. Other analyses make distinctions between direct and indirect advocacy. When it has to do with research, indirect advocacy may describe the participatory aspects of non-profit advocacy, particularly the capacity of groups to stimulate individual citizens to take action on their own behalf. In contrast, direct advocacy may refer to lobbying and other appearances before key decision makers by organizational representatives on behalf of others.

One of the most widely disseminated contributions to the debate in this area is contained in a draft statement of the Aspen Institute, an international non-profit educational institution headquartered in Washington, D.C. This statement, published in the fall of 2000, contained the results of consultations with business, government, academia, the media, non-profit organizations and foundations. In these consultations, one of the deliberations concerned the function of the non-profit sector and its role in promoting civic participation and advocacy. There were several points of agreement and disagreement. Advocacy was seen as a fundamental function, and active participation in the policy process a fundamental function of the non-profit sector in a democratic society, something to be encouraged in the future. It was observed that participation in the policy process can provide benefits such as focusing public attention on key social problems and solutions, increasing the base of knowledge on which sound innovative policy is formed, ensuring access for new and unheard voices, fostering governmental accountability to citizens, promoting democratic values such as freedom of expression, pluralism and self-

sacrifice shaped by a vision of the public good, and giving citizens a personal sense of efficacy and civic skills as players in the democratic process, as well as increasing their sense of attachment to the community.[4]

In Canada, a joint initiative launched to improve and strengthen the long-standing relationship of the federal government and the voluntary sector released a report in 1999. In this report, advocacy was defined as the act of "speaking, or of disseminating, information intended to influence individual behaviour or opinion, corporate conduct, or public policy and law. However, while the act of advocacy is merely a means to an end the nature of the public benefit which accrues needs to be considered."[5] The report identified problem areas for charities, including the boundaries between permissible charitable endeavour and impermissible political activity and between education and promotion of a point of view and the *Income Tax Act*, which has provisions limiting political activities by charities, and Canada Customs and Revenue Agency's (previously Revenue Canada's) specific interpretation of the Act's provisions.

In general, the rules in Canada may be summarized as follows. Education must not amount to promotion of a particular point of view or political orientation, or to persuasion, indoctrination or propaganda. A charity cannot have political purposes, but it may devote some of its resources to political activities as long as: they are non-partisan, they remain "incidental and ancillary" to the charity's purpose, and substantially all (90%) of the charity's resources are devoted to charitable activities.

Canada's Investment in Health Research – A Comparison

Canada is fortunate to have a world-renowned health research community. It has developed and been sustained on a relatively small investment in research compared to other member countries of the Organization for Economic Co-operation and Development (OECD). In the world ranking in gross expenditures on research and development as a proportion of gross domestic product for OECD countries, Sweden is ranked as #1 at 3.85, the United States as #6 at 2.6, and Canada comes in at #15 at 1.60.[6]

In the United States, the National Institutes of Health increased their 2001/02 budget for health research to US$2.5 billion. Figure 1 demonstrates a small improvement in per capita investment in health research and development in Canada; however, in comparison

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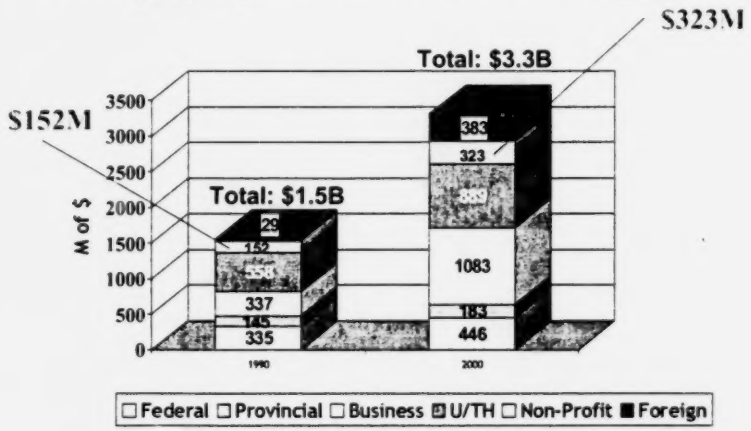
[4] The Aspen Institute. "The Nonprofit Contribution to Civic Participation and Advocacy: A Draft Statement for Public Discussion." The Aspen Institute: Washington, D.C., Fall 2000. Available online at http://www.aspeninst.org/nppf/pdfs/nssg.pdf.

[5] *Working Together: A Government of Canada/Voluntary Sector Joint Initiative: Report of the Joint Table* (August 1999). In June 2000 the Voluntary Sector Initiative was announced. A joint table made up of government and voluntary sector representatives was established to develop an accord. The Joint Accord Table developed a draft Accord and broad consultations took place across Canada during the summer and fall of 2001. Check online at www.vsi-isbc.ca/eng/joint_tables/accord or more information on the accord and at www.vsi-isbc.ca/eng/reports_wt/exec.cfm for the Executive Summary of the *Working Together* report.

[6] OECD Main Science and Technology Indicators, 1997 Data.

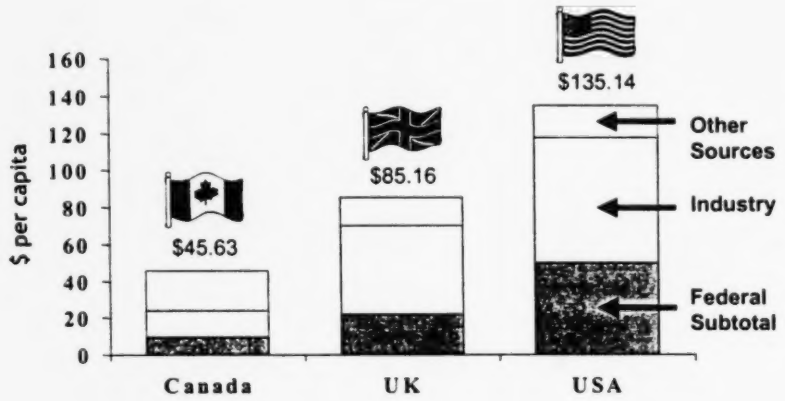
to the United Kingdom and the United States, Canada's per capita investments in health are still low (see Figure 2). Compared with selected countries from 1990-97, the premier funding agency for health research at the time, the Medical Research Council of Canada, demonstrated negative growth (see Figure 3). Despite this, Laval University in Quebec and Mount Sinai Hospital in Ontario ranked #1 and #10 among institutions having the most citation impact (1994-1998) by the Institute of Scientific Information (ISI). There was no doubt in the health research community that Canada needed to invest significant dollars in health research. (Health research in Canada has been funded by many organization and agencies ranging from hospital research foundations, to private foundations, to provincial governments, health charities and national government institutions, such as the Medical Research Council of Canada.)

Figure 1: Canada's expenditures on R&D in health: Leveraging improves from 1:5 to 1:7 in 10 years



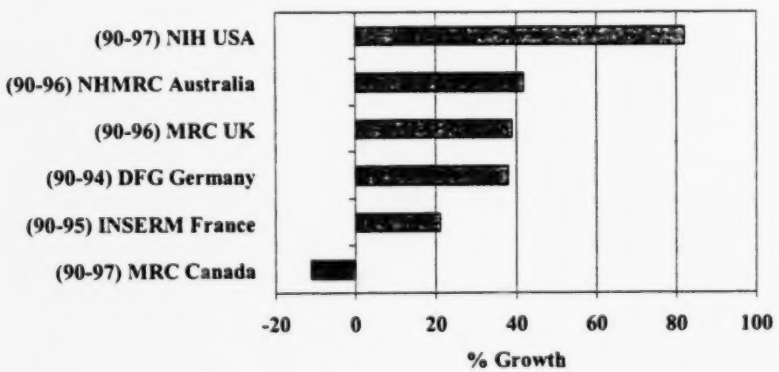
Source: Estimates of Canadian research and development expenditures (GERD), Statistics Canada (Gross expenditures on research and development)

Figure 2: Per capita investment in health R&D



Source: Canadian Institutes of Health Research (see: www.cihr.ca)

Figure 3: Canada's Health Research Budget Compared with Select Countries



Source: Canadian Institutes of Health Research (see: www.cihr.ca)

Responding to the Challenge

The Medical Research Council (MRC) of Canada used to be the major federal agency responsible for funding biomedical research in Canada. Its role was to promote, assist and undertake basic, applied and clinical research in Canada in the health sciences. It also had a major role in supporting research training of health scientists and acted as an advisor on health research to the federal Minister of Health.

In 1998, it was apparent that Canada was lagging behind a significant number of countries in its investment in research and a paradigm shift needed to occur in the type of research funded.

The Government of Canada responded to this challenge by establishing a task force under the aegis of the MRC representing the full spectrum of the research community. This task force proposed to the federal government a new, unique, made-in-Canada model for organizing and funding Canadian health research.

The health charities' community in Canada, while on one hand being extremely supportive of the government's desire to increase the amount of funding to health research in Canada, had significant concerns about the meaning of this to the health charities' sector in terms of its viability, especially in terms of fundraising.

As was already mentioned, there are over 175,000 non-profit organizations operating in Canada, and close to 80,000 of these are registered as charities with the Canada Customs and Revenue Agency. Of these, the vast majority are classified as religious charities, with 7.6 percent representing health charities. Almost half of all charities in Canada report revenues of less than $50,000. An additional third report revenues of $50,000 to $250,000. This means that only 19 percent have revenues of $250,000 or more and only 2 percent have revenues of $5 million or more. The voluntary sector accounts for one-eighth of Canada's GDP, with an estimated $90 billion in annual revenues and $109 billion in assets. The voluntary health sector allocates approximately $300 million each year to support health research. The health charity sector makes a significant investment to health research in Canada, and as such, its concerns needed to be addressed.

Health charities' concerns focused around several issues: 1) the impact that a significant government investment in health research would have on the public contributions to research funded by health charities; 2) the competition with government in terms of public visibility and credit for the funding of research; and; 3) a concern that health charities with a much smaller research budget would only be able to fund smaller grants to researchers and not be able to fund "cutting-edge" work.

The major health charities, which funded approximately $300 million a year in research, came together in a loose affiliation to have input into this process. One of the first activities undertaken was an Environics survey of the public on their beliefs and values about the charitable sector partnering with government in joint funding of research.

This initial work provided assurance to the health charities that the public, which they were mandated to serve, would not see this as a competitive issue, but rather as a way that the governmental and non-governmental sectors could work together to leverage resources for health research in Canada. Non-governmental organizations mobilized quickly to promote increased funding for health research in Canada. The techniques used were a combination of advocacy and lobbying.[7]

What followed was a real-life demonstration of what the literature and theory on this subject describes as effective advocacy strategies – the ability to mobilize a broad grassroots movement or its equivalent; representation through an organized constituency; a good understanding of how governments function and how decision-making takes place; a lobbying campaign; a legitimate claim on the public interest; an ability to frame the debate in terms which favour the desired course of action, and professionally sophisticated lobbyists.

The literature also describes how often this work is done through coalitions.[8] The advantages of coalitions are, for example: economies of scale, division of labour and reduced duplication, strength in numbers, a united front and consistency of message, a wider reach, a perception of broad community support, media control, an ability to reduce the risk of counterproductive activities, pooling of resources and cost efficiency. One of the challenges in mounting any advocacy or lobbying program is the ability to be there for the long haul. In advocating for increased research funding, the health community was able to demonstrate precisely these abilities and advantages.

Many groups work individually in the campaign of increasing research funding in Canada. However, this paper deals with two major groupings that work closely together very effectively in this area despite their different mandates. These two groupings are the Council for Health Research in Canada and the Health Charities Council of Canada.

Spotlight on Two Organizations: The Health Charities Council of Canada and the Council for Health Research in Canada

The results of the original task force deliberations, which included representatives of three health charities, recommended the establishment of an organization in Canada that would become a much larger and more encompassing health research granting agency.

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[7] For the purposes of this discussion, advocacy refers to the process of promoting certain positions or courses of action, usually implying a more specific process of influencing political decisions as they are made. Lobbying normally involves activities designed to influence or sway public officials toward a desired course of action.

[8] Utilizing a coalition approach is not new. Coalitions are often referred to as process coalitions and action coalitions. Process coalitions often consult around the issue to build ownership and are most suited for networking over a longer time frame with broader-based interests. Action coalitions, on the other hand, have a very narrow focus, a results orientation, and are most suited for public policy advocacy in government lobbying.

The recommendation was to establish "Canadian Institutes of Health Research" (CIHR), a family of virtual institutes organizing and funding health research in Canada.

As a result of this discussion, an Interim Governing Council (IGC) was formed. The IGC was a group of 34 distinguished scientists, leading academics, educators, health practitioners, social scientists and representatives from the voluntary and private sector who created a series of subcommittees to prepare working papers that would address key issues related to the CIHR. The health charities sector became an important part of the deliberations.

The IGC was co-chaired by the President and CEO of the MRC of Canada and the CEO/Executive Director of the Canadian Cancer Society and the National Cancer Institute of Canada. As well, to further the government's understanding of the contribution and role of the voluntary sector, the IGC included a volunteer representative of the Heart and Stroke Foundation of Canada. A staff person from one of the major health charities was seconded to the IGC on a part-time basis to provide direct input into the staff deliberations as they worked for the establishment of the CIHR.

The health non-governmental sector in Canada was also undergoing tremendous transition at the time, changing from a loose affiliation of health charities organized through the National Voluntary Health Association, part of the Coalition of National Voluntary Organizations, to a more formal organizational grouping, the Health Charities Council of Canada. This group was formally established in June 2000 and was the culmination of collective work of over 35 national health charities. Its mandate is to provide a collective voice for national health charities on common issues and concerns and to come together to affect policy and the broad areas of interest of research, health information/surveillance and community/patient support.

The Health Charities Council of Canada quickly formulated recommendations to the federal government regarding health research funding. The policy platform in the health research area was to increase the A-based budget of the CIHR to $1 billion annually over the next three years, increase funding to Health Canada by an additional $300 million annually for the next five years to better respond to the health needs of Canadians, and enhance the tax measures for modest donors to any registered charity (individuals whose combined donations are $2,500 a year or less).

The Health Charities Council of Canada, by defining health research as one of its major priorities through consultations with all its memberships, built a feeling of ownership for this issue. Staff in Ottawa made presentations before Standing Committees on Health and Finance. The Health Charities Council participated in meetings on Parliament Hill with federal Members of Parliament. At these meetings the joint strengths of the health charities were demonstrated. The presence of individuals who could relate the personal effects of health issues to the Members of Parliament, coupled with the presence of scientists able to reflect what increased health research dollars would be able to do in terms of managing these issues, provided a very powerful framework and background for Members of Parliament. The Health Charities Council also had direct meetings with

Members of Parliament in their ridings and constituencies, which proved to be a very effective grassroots approach.

The Council for Health Research in Canada is a national not-for-profit organization comprised of health agencies and research institutions with lay boards of directors that raise funds for health research. The Council was established in 1996 to influence the Canadian public and private sector through various strategies on the effect of increased funding for health research. This Council is an example of an action coalition – it was formed specifically to lobby around increasing funding for health research in Canada.

The current platform adopted by the Council for Health Research in Canada was a platform of $1 billion dollars for the CIHR as a worthwhile investment for government. This represents less than 1% of current health care expenditures and this amount of dollars would: further advance broader government priorities; stimulate an effective, biotech and life sciences knowledge-based economy; reduce the economic burden of illness in Canada; develop an innovative, cost-effective and evidence-based health care system; and, brand Canada as the place to be for health research in the 21st century. This lobbying platform of the Council for Health Research in Canada built on the direction proposed by the IGC in promoting the establishment of the CIHR.

Results

It is always difficult not only to measure results but also to attribute results in these types of arenas to specific actions. However, both the Council for Health Research in Canada and the Health Charities Council of Canada did play a vital role. In the 1999 federal budget, there was funding of $550 million over three fiscal years for new research initiatives, the establishment of a task force as described earlier under the aegis of the MRC representing the full spectrum of the research community, and a task force recommendation to establish the CIHR. This sustained, ongoing involvement and presence of these groups over the long term played a role in the establishment of the CIHR.

In 2000, the Government of Canada passed Bill C-13. Entitled the *Canadian Institutes of Health Research Act*, this Act established the CIHR, repealed the *Medical Research Council Act* and made consequential amendments to other laws. The new Act states that CIHR will engage voluntary organizations, the private sector and others in or outside Canada with complementary research interests. It also states that CIHR will communicate with the public, governments and the Canadian international research communities, voluntary organizations and the private sector on issues pertaining to health or health research.

For Further Research

Despite the examples of successful lobbying in the Canadian context and our belief that in the example just outlined the lobbying conducted to increase research funding was successful, there remain outstanding research questions in the area, including:

- the relationship between advocacy and effectiveness in achieving exempt purposes
- the effectiveness of different types of advocacy
- how organizations create an advocacy capacity
- the rationale for government to limit advocacy activities
- whether non-profit status and/or tax exemption is necessary for organizations to play effective roles as intermediary associations
- an identification of the necessary resources required for advocacy
- an identification of what kind of research and information are most useful to legislators or administrators for decision-making.

Conclusion

Susan D. Phillips, in her paper "Voluntary Sector: State Relationships in Federal Systems," observes that in most democratic countries there is a fundamental change taking place in the relationship between government and the voluntary sector. This is not because one or the other is changing – in fact, both the nature of governance and the voluntary sector are changing. Phillips says:

> Governments of both the left and right are also taking renewed interest in citizenship: in promoting voluntarism, an active citizenry and a vibrant civil society. The result has been a realization on the part of governments that they need the voluntary sector more than ever, not only as partners in service delivery, but in building social capital and enhancing social cohesion. On the other hand, the voluntary/non profit sector is evolving rapidly from a model based on charity to one based on civil society – that is, from a model premised on helping those less fortunate to one in which communities have resources and are empowered to represent and help themselves. This has sparked the emergence of strong national leadership aimed at providing strategic direction to the sector and the demands for new policy tools and citizen engagement in processes....The diversity of the voluntary sector should neither be underestimated nor ignored. Indeed, diversity is the sector's underlying strength, allowing flexibility in meeting a wide range of community needs, enabling representation of an enormous variety of particular communities and creating multiple routes of citizen access to collective action.[9]

[9] Susan D. Phillips, "Voluntary Sector: State Relationships in Federal Systems." Available online at the Forum of Federations site, at www.ciff.on.ca/References/documents/bg_papers/docbg_phillips.html.

By presenting this brief overview of how effective the voluntary health sector is becoming as an advocate for health research in Canada, this study has made two major points.

First, the important role of the voluntary health sector in advocating for improved funding for health research has been demonstrated.

But also, as described in the Introduction to this paper, the voluntary sector in Canada is large and diverse. Given the positive health consequences for Canadians that potentially result from the voluntary health sector's advocacy in this area of health research funding, and the fact that this is only one of its vital contributions, the true value of the voluntary health sector in particular and the voluntary sector in general to the quality of Canadian life must be enormous. One of the challenges that faces us is that it is also largely uncharted and therefore unknown.

Voluntary Health Sector – Integrators Across Health Domains

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November 27, 2001

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The opinions expressed in this paper reflect the views of the authors and do not necessarily reflect those of Health Canada, the Government of Canada or the Centretown Community Health Centre.

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Voluntary Health Sector – Integrators Across Health Domains

What Are We Talking About?

Several public policy interests of the Government of Canada intersect in the topic of the 'voluntary health sector.' Consideration of changes in the publicly funded health system is taking place at the same time as the federal government is directing policy attention to improving relationships with the voluntary sector. This examination of voluntary sector 'community health centres' illustrates the concept of 'community' as a key link between the two policy themes, and examines community health centres as integrators across determinants of health, communities, and sectors of society.

The Voluntary Sector Policy Direction

The Government's 1997 electoral platform expressed the renewal of the relationship between the government and the voluntary sector as a priority; the voluntary sector was noted as 'a vital third pillar in Canadian society, working alongside the public and private sectors to make Canada a more humane, caring and prosperous nation.' And the government pledged to work toward renewing the relationship, based on the view that "Today a new balance is emerging, based on the growing recognition that all three sectors are integral to our quality of life, the vibrancy of our communities, and the vitality of our civic and democratic institutions."[1] Recognition of the role that the voluntary sector plays in linking community to government has been expressed by the federal Government, when the Governor General said in his 1999 Speech from the Throne: "The government recognizes the need to build partnerships with communities and to renew its relationship with the voluntary organizations that serve and sustain them."[2] In order to make this new view a reality, collaborative and cooperative work in examining policy and practice has been underway for several years. Through the federal Voluntary Sector Initiative, government and the Sector are working jointly to implement an Accord, to increase public awareness of the sector, to change government policy and practice in its relationships with the sector, and to develop further knowledge about the sector itself and its role in society.[3]

Though not widely recognized, the voluntary sector plays a role in health, as it does in all other sectors of Canadian life. For example, the rapid and effective work of the American and Canadian Red Cross and the Canadian Blood Services among other voluntary organizations in September's terrorist attacks in the United States demonstrates the importance of the Voluntary Health Sector (VHS) in mobilizing volunteer effort, in channeling voluntary contributions, in partnering with other organizations, and in quickly responding in new and unknown situations.

As well as response to crisis and emerging issues, the VHS is a key player in all aspects of health, including prevention, promotion, protection and health services delivery. While individual organizations are well known, the sector as an entity is largely unknown and unrecognized.

Health Canada has done some preliminary work with voluntary health organizations in developing an appropriate policy framework. For purposes of this paper, the VHS is seen to include organizations ranging from clearly health-centred organizations such as the Canadian Cancer Society and the Canadian Diabetes Association on through to organizations whose mandate is health-related (e.g. the Canadian Council for Health and Active Living at Work), and on to organizations whose work affects the health of Canadians though their mandate is not health-centred – for example, the Canadian Criminal Justice Association, and l'Association québécoise de défense des droits des retraité(e)s et des pré-retraité(e)s.[4]

In a document jointly prepared by Health Canada and the voluntary health sector, the voluntary sector is defined as follows:

- "Consists of individuals and organizations whose activities are carried out primarily but not exclusively by volunteers;
- Has as its essential attribute the willingness of people to donate their time, knowledge, skills, energy and resources to assist fellow citizens;
- Is involved in activities designed to provide help to individuals, families, groups and communities; these "helping activities" include: direct service, information exchange, public awareness, education, support, fundraising, advocacy, research, public dialogue and policy development.

And, further

Voluntary organizations are defined as:

- Help to organize voluntary action and volunteers to: further a shared public interest or objective; provide services, supports and resources; and engage in dialogue and action.
- Do not seek profit as an end in itself.
- Are accountable to constituencies or members through democratic governing structures, and sometimes, legal frameworks.
- Encompass national, provincial, territorial, regional, local, grassroots and citizens' organizations.
- May have a financial relationship for which they are accountable, with governments, foundations, the private sector and citizens, but are autonomous and independent."[5]

Canadians put their money where their concerns are, through choices they make in charitable contributions to voluntary health organizations that are registered charities. (This includes organizations such as community health centres, the Red Cross, the Cancer Society, Heart and Stroke Foundation and many others.) In 1997, Canadians donated about $773 million to health charities, including hospitals. More than half of Canadians donated to health charities, which received a larger proportion of all charitable donations (38%) than any other sector.[6]

Research on this subject is just emerging, and the development of a conceptual framework to assist in determining which organizations would be included in the concept

has yet to be finalized. Preliminary work done several years ago under Health Canada auspices is informative,[7] [8] [9] and building on it would both enrich public knowledge and assist research efforts immensely.

The Primary Health Care Reform Policy Direction

After 35 years of operation, the well-being of Canada's publicly funded health care system is being questioned. Is the health of Canadians improving? Are taxpayers willing to pay what seem to be the inexorable costs of an aging population? What incentives will encourage change from fee-for-service billing methods to cost-effective, cost-contained payment systems? How can promotion, prevention and protection be strengthened? How can continuity of care and integration of services be improved?

The current focus of reform is on primary health care, which the World Health Organization (WHO) describes as "essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the community and country can afford...It forms an integral part of the country's health care system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and the community with the national health care system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing care process...Primary Health Care addresses the main problems in the community, providing promotive, preventative, curative and rehabilitative services accordingly."[10]

By way of clarification, a recent report prepared for Canada's federal, provincial and territorial deputy ministers of health cited further WHO definitions that clarify that primary health care is not: " . . . 'primary medical care', or only first contact medical or health care. It is intended: to reach everybody, particularly those in greatest need; to reach to the home and family level, and not be limited to health facilities; to involve a continuing relationship with persons and families."[11]

What role can voluntary health organizations play in reform of the health system? This paper examines the activities of 'community health centres' in Eastern Ontario within the framework of the determinants of health. It also explores how their extensive use of partnerships and their focus on building community capacity holds great promise for primary care reform.

Health Is...

First, a definition of 'health' is required to set the stage for this discussion. According to the World Health Organization, it is 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' [12] and 'Health is (therefore) seen as a resource for everyday life, not the objective of living; it is a positive concept emphasizing social and personal resources, as well as physical capacities.'[13]

The most prevalent model of primary health care is based in the medical model of dealing with individuals when they become ill. There is recognition of the value of prevention and education, but funding methods do not for the most part support this aspect of service delivery. While it seems likely that changes in financing and funding methods and in organizational/institutional arrangements may add rationality and some cost containment, it's not clear that they will address the underlying causes of why people get sick in the first place or influence ways of helping them stay as healthy as possible.

It is widely recognized that 'health' as defined by WHO, is a result of many factors and the interaction among them. Widening the focus of health system reform to the 'determinants of health' frame, and applying that lens to a population health approach might result in reducing illness, and more important, promoting wellness among various populations and the individuals within them, and thereby reduce pressures on the health services system. According to the Canadian Institute for Advanced Research, as much as 75% of health status is impacted by factors outside the health care system. These other 'determinants of health' include biological endowment, genetics, physical environment, and social and economic environment.[14]

By way of example, consider some recent health events in Canada: the Ice Storm which for several weeks in 1999 paralyzed daily living for several million people in Eastern Canada; water quality crises where thousands acquired water-borne bacterial infections; elder abuse; adolescent crime and suicide; psychiatric crisis; hunger, homelessness, and the related health problems that arise. How does health practice focussed on the illness of individuals address common problems of groups such as Aboriginal people, gays/lesbians, youth, seniors, and immigrants/refugees, or indeed to prevent problems in the first place?

Population Health and Determinants of Health

"The term 'population health' is used to describe the multiplicity and range of factors which all contribute to health. 'Determinants of health' is the collective label given to the multiple factors that are now thought to contribute to population health. While there is no agreement on a finite set or the relative importance of the determinants of health, a certain degree of consensus has developed over the past decade. Income and Social Status, Social Support Networks, Education, Employment and Working Conditions, Social Environments, Physical Environment, Gender, Culture, Personal Health Practices and Coping Skills, Healthy Child Development, Health Services, Biology and Genetic Endowment make up the set.

Unlike traditional health care, which deals with individuals one at a time when they become ill, population health strategies aim to improve the health of an entire population through broadly based preventive approaches that take determinants of health into account. Such preventive approaches ward off potential health problems before they have an impact on the health care system."[15]

As a concrete example, a public policy choice could be made on how to spend the average public sector spending on health care regarding 'flu.' For that amount ($2150 in 1999) 270 seniors could receive flu shots, and thus be protected from hospitalization, or the non-physician costs could be paid for one senior hospitalized for the flu.[16]

The federal government has recognized the importance of health promotion approaches. In the most recent Speech from the Throne, the Governor General said: "The Government will also champion community-based health promotion and disease prevention measures."[17] And, in response the Prime Minister said: "We will work with and support provinces to make our health system more integrated, more effective, more responsive and more transparent."[18]

It is worth noting that some have criticized the emergence of a population health approach because "it offers a fundamentally different vision of health from that of health promotion." Another observer argues that "the ascendance of population health reflects a government retreat from the welfare state. What is especially concerning is that population health ideology, focus and methods are embedded within epidemiological modes of thought . . . (that) offer a fundamentally different vision of health from the values-based, pluralistic and community-oriented vision of health promotion."[19] Nevertheless the population health approach provides an expanded way of viewing health and points to more comprehensive approaches for improving well-being for the broader community.

Description of Health in Canada

"Canada has a predominantly publicly financed, privately delivered health care system. It provides access to universal, comprehensive coverage for medically necessary hospital, inpatient and outpatient physician services.

Canada does not have 'socialized medicine', with doctors employed by the government. Most doctors are private practitioners who work in independent or group practices, enjoy a high degree of autonomy, and are generally paid on a fee-for-service basis.

The federal government, the ten provinces, and the three territories have key roles to play in the health care system in Canada, known to Canadians as Medicare. The federal government is responsible for: setting and administering national principles or standards for the health care system (for example, through the Canada Health Act); assisting in the financing of provincial health care services through fiscal transfers; delivering direct health services to specific groups including veterans, native Canadians living on reserves, military personnel, inmates of federal penitentiaries and the Royal Canadian Mounted Police; fulfilling other health-related functions such as health protection, disease prevention, and health promotion.

The provincial and territorial governments are responsible for managing and delivering health services planning, financing, and evaluating the provision of hospital care, physician and allied health care services managing some aspects of prescription care and public health."[20]

Today, all provinces administer insurance plans guided by the common pan-Canadian principles enshrined in the Canada Health Act: universality, portability, public administration, accessibility, and comprehensiveness. (But) Canadians also use other types of health care. "Drugs, home care, nursing homes, dental care, physiotherapy, alternative therapies and other supplementary services are funded through a complex mix of public and private insurance and out-of-pocket payments."[21]

The governing legislation, the Canada Health Act, also contains provisions that ban extra-billing and user charges: no extra-billing by medical practitioners or dentists for insured health services under the terms of the health care insurance plan of the province or territory; no user charges for insured health services by hospitals or other providers under the terms of the health care insurance plan of the province or territory.[22]

Current Issues in the Canadian Health System

Canada's 'Medicare' system has been examined numerous times over the years, as pressures of sustainability and effectiveness gain public and political attention. A new federal Commission has been appointed to look at how the system can be sustained (Romanow),[23] and a committee of Canada's appointed Senate is undertaking a separate investigation (Kirby). [24] Reports from both are expected in 2002. Reports from several provincial examinations are in (Clair in Quebec,[25] Fyke in Saskatchewan[26]), and a report from Alberta is expected in the near future. From the point of view of the federal interests, the mandate of the Romanow Commission perhaps summarizes issues most succinctly: ". . .to recommend policies and measures respectful of the jurisdictions and powers in Canada required to ensure over the long term the sustainability of a universally accessible, publicly funded health system, that offers quality services to Canadians and strikes an appropriate balance between investments in prevention and health maintenance and those directed to care and treatment."[27]

In August 2000, leaders of provincial and territorial governments stated their key goals of health systems in Canada are to: preserve, protect and improve the health of Canadians; ensure that Canadians have reasonable access to an appropriate and effective range of health services anywhere in Canada, based on their needs, not their ability to pay; and, ensure long-term sustainability so that that health care services are available when needed by Canadians in future years."[28] Their top priorities were: access to care; health promotion and wellness; improvements to primary care; action on health human resources; home care and community care; action on pharmaceutical management; health information and technology; and, health infrastructure (equipment/technology).[29]

Subsequently, Canada's First Ministers (leaders of 12 provincial and territorial governments and the federal government) reached agreement in September 2000 on an Action Plan for Health System Renewal. This statement of principles will shape reforms in the future. Of particular relevance to this paper is the Ministers' vision of a Health Care System which "provide(s) greater integration of hospital, primary, home and community care, more emphasis on health protection and promotion," and their commitments to "promote those public services, programs and policies which extend

beyond care and treatment and which make a critical contribution to the health and wellness of Canadians."[30 31]

Health care spending has increased. The Canadian Institute of Health Information (CIHI) estimates that the cost of health care topped $95 billion in 2000, 6.9% more than the previous year." CIHI further reports that Canada is also spending more on health than most other countries. "In 1998, Canada ranked third among G-7 countries in terms of expenditure per person, behind the United States and Germany. Only the United States used a higher share of its economic output on healthcare (13.6% of their gross domestic product in 1998). In the same year, Canada's rate was 9.3%."[32] The Kirby Committee also points out that 69.6% of Canada's total health expenditures are funded publicly, while in the U.S. the proportion is 44.7%. However the public health care expenditures of the two countries as a proportion of GDP is nearly equal at 6.6% and 6.1% respectively.[33]

Other concerns have also been noted. "Evaluations of current fee-for-service [arrangements with physicians] note a lack of accountability for coordination of care, integration and a lack of focus on health promotion and illness prevention. Moreover, funding is procedure oriented and does not adequately support prevention/promotion activities."[34]

Issues of planning, coordination and integration were highlighted through a report released in 1999 by the Federal /Provincial /Territorial Advisory Committee on Population Health. This report stressed that "improving the health, well-being and quality of life in the population requires. . . intersectoral action - cooperation and collaboration within and between organizations and sectors, and it must involve the public and government sectors, the voluntary sector, the private sector, businesses, professionals and consumers in the fields of health, justice, education, social services, finance, agriculture, environment and so on."[35]

Individual Canadians are also concerned about the future of the publicly funded Medicare System. Health care continues to be a major priority for Canadians, and has been identified as a top national issue in polling results since 1998.[36]

In this context, this paper now narrows the focus toward primary health care reform.

The Response through Primary Health Care Initiatives

All Canadian provinces have been devoting considerable time over the last several years to the importance of primary health care and ways to improve the system. The Ontario Government asked its Health Services Restructuring Commission to examine, as part of a broader study of health services, the state of primary care in the province. In December 1999, the Commission produced its report on Primary Health Care Strategy. This report cited several reasons for focussing on primary health care:[37]

- It is the first point of contact for the health system – over 90% of Ontario residents have a long-term relationship with a primary care physician, primarily in private practice.
- Of the $4.3 billion spent under the Ontario Health Insurance Plan, 40% is for primary care physician services, with an additional $146 million supporting specific programs or paid on a capitation basis.
- Hospital emergency services are being used inappropriately by people who could be cared for in primary care settings if the services were more accessible.
- Accessibility to primary care is significantly limited in rural and northern communities, partly because of physician shortages.
- The population is aging and chronic disease increasingly prevalent.
- Present primary care services are "fragmented, unstructured" and "not well coordinated. Continuity of care is often compromised."[38] "Professional boundaries often frustrate collaboration"[39]
- Health care expenditures are rising, and governments are looking for ways to contain costs effectively.

The Commission pointed out in its Action Plan that "There is, in fact, no real 'system' of health care in Ontario. Hospitals, other health facilities, agencies, etc., interact and work together with health professionals at a number of levels. However, no identifiable 'system' or overall 'structure' supports them and/or community organizations so that they can function *together* for the benefit of patients, and their communities. In the absence of a co-ordinated system, continuity of care suffers. In addition, cost-savings and the quality-enhancing synergy of systemisation are lost – and in a time of dwindling resources."[40]

The Commission stated "An effective system of primary health care helps us to stay healthy, treats the majority of our illness, advocates for the health care of consumers and connects them to the rest of the system when they need other health-related services." Its vision – "All Ontarians will have access to comprehensive primary care services. Primary care will be the first point of access and the connector to the rest of the system."[41]

Prior to that report, the Ontario Medical Association, in collaboration with the Ontario Ministry of Health and Long Term Care, announced that reform of primary care was underway. Three years ago, on the recommendation of a Primary Care Reform Steering Committee, they launched several pilot projects to demonstrate the feasibility of physician-centred models of care (Primary Care Networks). The goals were to improve access, quality and continuity of care, and patient and provider satisfaction, as well as to increase cost-effectiveness of health care services.[42] These PCNs featured 24/7 service with telephone triage, physician group practices (virtual and actual), enrolment of clients and either capitation payments on the basis of client enrolment or "reformed fee-for-service" payments. The funding formula also built in some recognition of work related to preventive care, home care supervision and case conferencing.[43]

Many of the family physicians who have joined these networks are interested in two key elements: better accessibility and service for their clients, and better working conditions for themselves. The network model offers specific provisions to fund nurse practitioners, but as of March 2001 only 7 were employed by networks[44] in comparison to 145 physicians.[45] Other health professionals are mentioned as well but it is not yet evident how they are being incorporated into the model. The Evaluation Report on these pilots notes that "there is no community input into the governance of the PCNs" and raises the question "Is there a role for increased community involvement in governance?"[46]

In March 2001, the two partners announced an agreement to set up Family Health Networks, including an independent province-wide organization that would help more physicians participate in the new model of service. These are still early days for the initiative and uptake is relatively slow. The Ontario government hopes to have 80% of all family physicians operating within these networks by 2004.

Community Health Centres — A Voluntary Sector Model of Primary Health Care

Against this backdrop of public policy interest, the role of one mechanism for delivery of primary health care through a voluntary sector participant in Canada's health care system may hold particular promise for health care reform. Voluntary sector 'community health centres' (CHCs) provide a model for meeting a wide range of primary health care needs of Canadians. As community-based organizations, CHCs carry out their primary health care functions through multidisciplinary staff teams and inter-sectoral partnerships across communities. What strengths does the voluntary sector CHC model bring to primary health care? What can we learn from this model of voluntary sector engagement in health?

Literature Review

A literature search regarding "community health centres in Canada" resulted in 15 sources over the past 30 years. The first was published in 1972: the Hastings Report[47] described CHCs and the promise they held for a health promotion approach to improving health of Canadians. In the following decade (1972 - 1982) two articles provided descriptions of how CHCs were functioning in some cities.[48] [49] In the second decade following the Hasting Report (1982 - 1992), authors examined topics such as the potential threat of CHCs to fee-for-service medicine, and explored some policy implications.[50] [51] [52] [53]

Since 1992, three provincial governments have published descriptive information about CHCs (Saskatchewan,[54] Ontario[55] and BC[56]) and two doctoral dissertations relating to CHCs were completed.[57] [58] A chapter in a nursing management textbook examined CHCs as innovators in health management and delivery.[59] And, a community development practitioner in a CHC described the link between the community development method and CHCs as a model for primary health care delivery.[60]

As well, several publications explored the potential of CHCs in primary care reform. Denise Albrecht describes the characteristics of CHCs and promotes their potential as 'the model with the best potential' in reorganization of primary care.[61] She links the values underlying the CHC model to Canadians' fundamental value of universality. Suschnigg takes a sociological view in her focus on primary care reform in Ontario.[62] She reviewed the development of CHCs in Ontario, and provides a review of the provincial government's examinations of primary care reform. She concludes that "upcoming reforms will reflect a reductionist approach to health planning: a preoccupation with programs targeted at individuals. . .which will continue to distract attention from social, economic and environmental factors that undermine health." Suschnigg further concludes that "while recent reforms may help create a more equitable distribution of power among health care providers themselves, 'ordinary' (sic) citizens will continue to have little opportunity to participate in health planning decisions at the local level."[63]

Finally, Hoffman, Parent et al. write from the perspective of a local CHC (the long-established Sandy Hill Community Health Centre in Ottawa), and make a case for CHCs as a cost-effective solution to primary care reform.[64] A useful inclusion in this article is a physician's-eye view of the strengths and weaknesses of working in a CHC.

CHCs – General Description

In Ontario, the community health centre model emerged over 30 years ago as a result of actions by grassroots community members to bring better health and social services to their neighbourhoods. While the origins of centres differed from place to place, their common vision was to create a multidisciplinary centre to offer integrated, coordinated and accessible primary health and social services, crisis intervention and social supports at the local level. The range and specifics of the services offered were to reflect the needs of the respective communities, and the centres themselves were to be answerable to volunteer boards of directors elected from the community. Accountability to community members remains at the heart of community health centres and is reflected in requirements for annual meetings and reports, as well as active consultation for strategic planning and program development. It also drives the centre's community development activities, which aim to build the capacity of community members to identify and take action on local issues ranging from traffic calming to community gardens to local economic development.

The first centres were funded in the early 1970s by the Ministry of Health, which was persuaded by the findings of extensive community needs assessments and the concept of an interdisciplinary service model. Since then, 56 Ontario community health centres have been funded in a variety of settings – urban core, suburban, rural, northern and Francophone communities. Many more communities are mobilizing to get their own CHC. In 1994, the Aboriginal Healing and Wellness Strategy provided funds for 10 Aboriginal health access centres, some in northern areas and others in urban centres like Ottawa and Toronto.[65] These centres are members of the Association of Ontario Health Centres, an organization that acts as an advocate for the community health centre model,

and provides a focal point for coordinated efforts in such areas as evaluation and the sharing of information and expertise. Centres also collaborate at the regional level on policy development, coordination of services, evaluation and information sharing.

In addition to their governing principle of community control, from the outset the centres have been in the forefront of health promotion strategy. The determinants of health are the basis on which boards and staff plan and carry out their strategic visions. This means that the scope of their work extends far beyond the treatment of individuals and families. Community health centres reach into the broader life of a community to tackle issues such as poverty, inadequate housing, and community safety. Drawing from the make-up of their individual communities, centres may focus particularly on making health and social services more accessible for hard-to-serve groups – for example: recent immigrants, Canadians from different cultural groups, the gay/lesbian/bisexual/transgendered (GLBT) community or homeless men and women of all ages.

These guiding principles of community control and health promotion contribute to a model of service that actively seeks and engages partners from all sectors – government, non-profit agencies, community associations, faith organizations, other health service providers and business. Centre staff frequently become brokers, engaging sometimes very disparate partners to work together on issues that will benefit the general community or a particular group. At the same time, by promoting active partnerships with public health agencies, hospitals and other health providers, community health centres can be catalysts for better integration of the larger health system that includes primary care, acute care, long-term care and mental health services. The long-term result should be increased access and equity of service for the community, a better quality of life for individuals, families and neighbourhoods, and more effective use of scarce health and social resources.[66]

Description of CHCs in Eastern Ontario

The focus of this paper is the Eastern Ontario Network of Community Health Centres. The Network comprises 13 centres that, taken together, are a microcosm of the centres across the province – small and large, urban, suburban and rural, Francophone and Aboriginal. Seven Ottawa centres (including the Wabano Centre for Aboriginal Health) also work cooperatively with one another, and six have an active coalition with local Community Resource Centres, especially on social action and community development initiatives. (The following information results from Marguarite Keeley's questionnaire to the 13 centres, with a 100% response rate. The questionnaire was followed with in-depth personal interviews with board and staff members of the organizations.)

Components of a Community Health Centre

Each community health centre is incorporated as a not-for-profit corporation governed by a community board of directors. Board size can vary from centre to centre, and may include representatives from other organizations and agencies. In some cases, the centre

staff can also elect representatives to sit on the board. Nevertheless, the centre's members elect the majority of board members from the community at large. Boards use different governance models but are generally policy boards concerned with strategic direction, broad policy matters, financial trusteeship and social action/advocacy. The Board hires the Executive Director who manages the centre on its behalf and is fully responsible for all aspects of the operation.

The size of the centre and the composition of its workforce clearly depend on the size of the community served. For the Eastern Ontario Region, it can vary from 10 to 15 people (including administration) in a small community to well over 100 people in a large downtown area. Because it is a multidisciplinary model, a community health centre can employ a wide variety of health professionals – family physicians, nurses, nurse practitioners, social workers, health promoters/educators, dieticians, chiropodists, psychologists, child care workers, mental health specialists, youth workers, substance abuse counsellors, community developers and outreach workers. Specialists (psychiatrists, for example) may be contracted as needed. Core administrative functions comprise finance, administration, clerical and reception services, and may include a health planner, human resource officer, information technology staff and volunteer coordinator if the centre is very large. Core administration is generally 5% to 10% of total expenditures. Volunteers form an important core of community support, offering their time and efforts as board members, program helpers, drivers, cooks, fundraisers, and researchers. The annual economic value of volunteers to all Ontario community health centres was estimated to be in excess of $11 million in 1999.[67]

Most community health centres serve a defined geographic area and their services are free of charge to anyone living in that area, regardless of income. Basic services and programs include primary care, counseling, health promotion, and outreach and community development. Other programs may target community members who are hard-to-serve or disadvantaged in some way. Depending on community need, the specifics of program delivery can vary. For example, a centre in the urban core may offer targeted services for homeless men and women and for the frail elderly in assisted housing, while suburban centres may focus on youth and family services. A wide variety of other programs is offered, ranging from community kitchens to parent-child drop-ins, community mental health services, infant development and infant stimulation programs, speech and language services, chiropody, physiotherapy and diabetes education. Centres whose clientele is Francophone or Aboriginal offer linguistically and culturally appropriate services to their clientele, drawing from the broad spectrum of possible programs.

Most centres are open some evenings as well as five days each week. On-call medical services are offered 24 hours a day and 7 days a week for centre clients. Many of the Eastern Ontario centres offer their clients walk-in services during normal working hours. In addition, the walk-in clinics of several Ottawa centres serve homeless families and individuals, people without health insurance (e.g. refugees) and people requiring social services. The Eastern Ontario Network also collaborates to provide programs that a

single centre could not, such as chiropody, speech and language services and diabetes education.

A wide variety of health promotion and health education groups is offered during the day and in the evening. These include seniors' exercise, stress reduction, vegetarian cooking, exercise and depression, well baby clinics, peer support for abused women and ethnocultural support groups, to name a few. Allied agencies may also rent offices in the same building or co-locate with centres because they are serving the same clientele and wish to create opportunities for better collaboration. These can include housing agencies, services reintegrating offenders into the community, legal aid and immigrant services, among others. Many centres also offer their space to like-minded community organizations for meetings, workshops and conferences, often free of charge or at a nominal rate.

The Ontario Ministry of Health and Long Term Care, Community Health Centre Program, provides the majority of funds for community health centres in Ontario. Many centres also receive ongoing and special funds from other areas of the Ministry, other ministries (e.g. Community and Social Services, Colleges and Universities) and federal and municipal governments. Frequently, health centres have been successful in attracting funds from foundations at the community and provincial levels for specific programs. Donations from service clubs, local businesses and individuals also help support targeted programs, but this revenue source does not form a large percentage of centre funding. Annex A to this paper shows the range of partnerships undertaken by a sample of CHCs in Eastern Ontario.

The Community Health Centre Model: Grounded in the Voluntary Sector

The foundation of the community health centre is its community. The community influences the health centre at all levels of development and operation – what the centre does, why and how. In the first instance all CHCs originate in people who come together around health issues and needs, and who decide to organize their neighbours to build a case for a community health centre. These voluntary efforts at the grassroots carry over into the governance of an operating CHC as a not-for-profit corporation with a board of community volunteers. Through formal bylaws, annual meetings, and regular client and community consultation processes, the community health centre maintains its accountability to its roots and reflects community needs in its programs and services.

This connection to community is expressed in vision and mission statements that set out a broad and deep definition of health, a definition that extends beyond the individual to the whole community, beyond the absence of illness to the promotion of wellness for individuals, families and the community at large. This vision recognizes the CHC as a vehicle for improving health, and leads to a focus on partnerships – with individuals on their own health concerns, and with community organizations and other agencies on broader social issues. It signals a fundamental role of the community health centre to build the capacity of individuals and communities to take action to improve their own health conditions.

The Vision and Mission Statements for Centretown Community Health Centre in Ottawa illustrate the breadth and depth of this approach to health:[68]

> **Vision**
> Centretown Community Health Centre envisions a community in which:
> 1. People of every race, culture, language, faith, gender, age, sexual identity, family status, income level and health status are valued members of our community and can participate fully as citizens;
> 2. All people deserve to have access to adequate income, employment, health services, education, food and shelter, transportation, recreation and culture;
> 3. People must have the means to act on their own concerns, working with others to meet their needs and improve their well-being;
> 4. When a full range of community services is in place people can access the supports they need to reach their full potential;
> 5. By living, working and playing together, individuals and organizations can develop a strong community spirit and contribute to building healthy communities.
>
> **Mission**
> Centretown Community Health Centre is committed to the health and well-being of all people within the communities we serve. We offer health and social services that are responsive to the changing needs of those we serve and are accessible to all. Through leadership and support, we foster the active participation of individuals and groups in a common effort to build healthier communities. CCHC provides a full range of health and social services to individuals and families who live or work in Ottawa South, the Glebe and Centretown and specialized services to all residents of the broader Ottawa region.

Each CHC carries out its mission through a service delivery philosophy that clearly reflects its community roots. Its services are client-centred, respecting a person's understanding of their own needs and involving them in decisions about how to improve their health and quality of life. The approach to health issues is holistic – seeing the whole community and the individual's place in it. Multidisciplinary teams within the CHC work together to respond to the array of needs and situations presented. The holistic view of health combined with the recognition that the centre must work with people individually and collectively to address concerns results in a basic CHC strategy to collaborate and cooperate with a variety of other actors to achieve healthy outcomes. To promote wellness, the CHC reaches out to people where they are, helps them develop the capacity to act on their health needs, and connects them to other partners that share common cause. This is the CHC as an integrator, a catalyst, a bridge between different community interests and between the traditional health system and the community itself.

The vision and mission of a CHC and its service delivery philosophy are the statements of principle that guide its development and operation. These statements clearly define the CHC in relation to its accountability to its community and to its broad focus on health

and community empowerment. The name "community health centre" is, therefore, not simply a nice choice of words. It is in effect a "brand name," denoting a very specific approach to individual and community health. The "brand" comes with a guarantee of sorts, because the CHC's foundation in the community has become formalized, or institutionalized if you will, through two significant processes.

The first is accreditation, Building Healthy Communities, which is carried out by an independent organization and teams of peer reviewers on a three-year cycle. There are five building blocks for accreditation: governance, management, administration, community capacity and programs and services. Each one contains elements that "bind the CHC to its community."[69] For example:

1. The centre must be a non-profit corporation with a voluntary board that represents the community it serves.[70]
2. Management accountability is expected to reach "outside the walls of the CHC, speaking to the interests of funders, and community partners."[71]
3. Administrative systems and practices are assessed, among other things, for their physical, cultural and social accessibility to communities and clients.[72]
4. Community capacity includes an assessment of how well the CHC involves its clients in different roles (as clients, Board members, program volunteers) and of the ability of the CHC to enter into partnerships and "work collaboratively to respond to community priorities."[73]
5. Programs and services are assessed for how well they "respond to the whole person (individually or in groups) in an integrated way."[74]

The second process that institutionalizes and "guarantees" the CHC "brand" is the framework that guides the evaluation of the CHC's program effectiveness. This framework was recently developed by CHCs through their provincial association, and has been endorsed by the primary funder, the Ontario Ministry of Health and Long Term Care. The indicators by which a CHC is assessed fall under five categories: accessibility, holistic and client-centred service, individual and community capacity-building, comprehensive programs and services delivered through multidisciplinary teams, and focus on wellness and prevention. Few if any of these evaluation categories could be demonstrated by a health agency that is not grounded in the community and its voluntary networks.

As a result, for a health agency or organization to call itself a community health centre in Ontario, it has to be a non-profit voluntary agency with accountability to its community, a demonstrated commitment to health promotion and a particular community development focus for its service delivery.

The network of community health centres in Eastern Ontario provides ample illustration of how these principles and requirements are carried out in the real world. Whether urban, suburban or rural, whether serving a geographic community or a particular population (French-speaking residents or Aboriginal people), all centres use partnerships throughout their program spectrum: health promotion, early intervention, chronic disease

management, social action and community capacity-building. The partners are many and varied, and become involved because of their particular interests and resources and because of a common focus on a target group or health concern. The partners include hospitals, public health units, other CHCs, voluntary health associations (the Canadian Diabetes Association or the Arthritis Society, for example), schools, social agencies, churches and faith organizations, all levels of government, housing agencies, universities, community associations, service clubs, businesses and the police.

Frequently a single program involves several partners, with the CHC as the connector. Different groups and agencies can contribute different things – for example, space, program supplies, funds, materials, advice and expertise, volunteer and/or staff support. CHC roles can also differ in the partnership depending upon what is being asked of them and what they are best able to offer. These roles can include any or all of the following: management and coordination, advice and expertise, space, materials and supplies, training and supervision, staff and volunteer support and, in some cases, funds. The network of support for a given initiative reflects what each partner can best contribute.

A survey of the Eastern Ontario CHCs shows that this strategy of working in partnership extends to the full spectrum of possible target groups whether defined by age, gender, income level, cultural group or health issue. The specific focus depends on the community served by the CHC and the nature of the initiative. So for example, a large downtown CHC may have strong partnerships targeted at services to the GLBT community or homeless men and women while a rural community may have focussed partnerships dealing with youth at risk or isolated seniors.

Annex B to this paper provides a summary of information about CHCs in Eastern Ontario.

Community Health Centres – Integration in Action[75]

It is worth examining some specific examples of what CHCs do in order to illustrate more clearly how they work collaboratively with community members and partners to achieve results that influence the determinants of health for their communities. These examples or case studies demonstrate the characteristics of CHCs that make them an effective model for positive reform of the primary health care system.

1. Building Community Capacity – Carlington Health and Community Services

Through their strategic planning consultations, the CHC Board identified many service needs for the families in a low-income rental housing neighbourhood. The six market-rent buildings housed about 500 families. Tenant turnover was very high and the environment was unsafe for residents. While it was in the CHC catchment area, this neighbourhood was just far enough from the centre to limit accessibility to services offered there. The murder of a child in the neighbourhood prompted a local Rotary Club to go to the CHC offering their help if the CHC staff would show them what to do.

The CHC met with residents who identified the need for programs that would address community safety concerns, provide stimulation for children and youth, and support families in difficulty. Together with the CHC and the Rotary Club, the community undertook to bring in a range of health and social services, and to involve residents in making their neighbourhood safe. The CHC set up a satellite medical clinic, provided the services of a community developer to work with residents on their concerns, and acted as the broker to bring in services from other agencies.

Today this neighbourhood has core medical services, infant stimulation and children's programs, a "baby cupboard" with clothes and toys, a computer club and a literacy program. They started a Neighbourhood Watch program and have seen the numbers of calls to the police go down substantially. They have built a park and set up a Good Food Box Club (that offers fresh vegetables and fruit at low cost because of direct purchase from a supplier). Many of these programs are supported by volunteers from the Rotary Club and from the community itself. The result is a community where tenant turnover has been reduced, residents are active in helping offer community services, and the neighbourhood is a safer place.

This satellite program involves many partners: the CHC as the integrator, broker and provider of medical services; the Rotary Club as a source of funds, in-kind resources and volunteer program leaders; churches offering volunteers, funds, and in-kind resources; the local food bank; a youth services agency; the Boys and Girls Club; and, the landlord, who provided space for programs.

This neighbourhood project is addressing several determinants of health: income and social status, social support networks, social environments, physical environments, personal health practices and coping skills, healthy child development, and health services. The catalyst and connector is the community health centre.

2. Health Education – Chronic Disease Management – Centretown Community Health Centre

Recognizing that Type 2 Diabetes is a growing health problem, the Ontario Ministry of Health decided to invest in new approaches to provide diabetes services at the community level. With the support of the Ottawa Coalition of Community Health and Resource Centres, the CHC took the lead in establishing the Ottawa-Carleton Diabetes Services Network. This network brought together all the key players offering diabetes services – four local hospitals, the public health department, the Canadian Diabetes Association, and the Community Care Access Centre – with the purpose of identifying service gaps, planning coordinated interventions, and ensuring effective use of resources. Through coordinated planning, the network aims to ensure that people receive the level of service they need from the appropriate service provider. At the community level, primary care education and support is managed and operated by CCHC.

The program itself comprises group education sessions with follow-up and individual support. The key staff are a nurse educator and a dietician who deliver the program in a variety of locations throughout the greater Ottawa area. In 2000-2001, more than 50 sessions were offered to over 600 people in four languages besides English and French, and assistance was provided to an Aboriginal health access centre. The team also trains trainers in other centres, and has developed a trainers' guide that has been sold across Canada, along with a modified Canada Food Guide for people with Type 2 Diabetes. All client materials are available in several different languages.

People can register themselves in the program or be referred by one of the partner agencies. Some clients are now being referred by private physicians after outreach by the team to let physicians know about the service. The program is a great success and is being used as a model nationally. Clients have reported significant improvements in their health, and are making sure they keep up the practices learned. Hospital specialists are reporting fewer people using their services when they could more appropriately served by the CHC program.

This program amply demonstrates the range of partners that can be brought together to focus on a disease with significant health and resource implications, and to develop a more effective approach to care. The health determinants implicated are education, personal health practices and coping skills, health services, and culture.

The CHC played the lead role at the strategic planning level – bringing together all the key partners in diabetes – and at the management and program coordination level. By developing guides and materials, and by training other service providers, the team has disseminated the model so other communities can benefit from their experience.

3. Cultural Connection for Homeless Aboriginal People – Wabano Centre for Aboriginal Health and Sandy Hill Community Health Centre

Staff at the Wabano Centre for Aboriginal Health in Ottawa were concerned about the large number of homeless Aboriginal people in the downtown core, but could not effectively reach out to them because their centre is not located downtown. Wabano staff approached Sandy Hill CHC, a sister CHC in the urban core. The result is Biindahgen, a program that provides medical, social and practical support in a culturally appropriate way to homeless Aboriginal men and women, and those at risk of homelessness. Sandy Hill CHC provides a meeting room where Aboriginal clients come weekly to get help with medical, social, mental health, addictions and housing problems. Aboriginal elders offer counseling, and clients can eat Aboriginal cooking and participate in crafts, such as the making of medicine bags. After 18 months, 25-30 people come each week to participate in a safe and comfortable place. Wabano manages the program, provides the funds, supplies and volunteers while Sandy Hill offers space, medical assistance and other staff support. Other partners have joined the program to extend the range of supports available – Pinganodin Lodge, the Aboriginal Support Centre and the Canadian Mental Health Association.

The Wabano Centre is the only CHC in Ottawa with the cultural knowledge to craft a meaningful and supportive program for homeless Aboriginal people. Their willingness to look for a partnership with a downtown CHC brought their collective resources to bear on a service that addresses issues of income and social status, social support networks, social and physical environments, personal health practices and coping skills, health services, and most important, culture.

4. Nutrition Services in a Rural Community – Merrickville and District CHC

The Merrickville and District CHC serves a large rural area southwest of Ottawa. Staff at one of the rural schools noticed that many of their students were arriving after a long bus ride without having eaten any breakfast. They realized this created learning problems for their students but were not sure how to raise the matter with parents in a positive way. The School approached the CHC because its staff complement includes a nutritionist. With her help, the Morning Snack Program was launched. The program now provides nutritious snacks to all students (about 200 from grades one to eight) when they arrive at school. All parents are asked to contribute $4/month, but students can participate whether or not their parents have contributed.

The CHC role was key; the nutritionist offered advice about nutritious snacks, and provided program coordination. The CHC has provided organizational support and encouragement so the parents' council can take over program operation. It also acted as a catalyst to bring together parts of the community that had not worked together before. Local businesses provide cash donations and volunteers; the school offers space and in-kind resources; the parents' council provides volunteers, raises funds, and publishes a newsletter.

The community has rallied around this program, and has also developed awareness about the importance of a healthy breakfast for children to be able to learn. It is a simple program with significant health impact, addressing healthy child development, personal health practices and coping skills, social environments, education and social support networks. The CHC was crucial in providing a health-based justification for the program, forging links between the school and the business community and building the capabilities of the parents' council to take over responsibility for the program.

5. Forging New Partnerships in Mental Health – Sandy Hill CHC

A community mental health planning group in Ottawa had been trying for many years to secure funds for a crisis counselling service for individuals to get the help they need and still remain in their community. When the provincial government finally approved funds, the group approached the Sandy Hill CHC to manage and operate the program. The service provides crisis intervention, support and community links to people 16 years and over who are experiencing a mental health crisis and to their families so as to help them stay in their home environment.

This is a brand new program that provides 24-hour service to the greater Ottawa area through a telephone line and a mobile crisis team. It is a unique partnership of the Ottawa Hospital, the Sandy Hill CHC, the police, numerous mental health agencies and consumers. Funds flow through the hospital to the CHC and the program features a shared governance model. The police have seconded five specially trained officers (in plain clothes) and provided a vehicle to the team. A committee of consumer organizations and community mental health partners provides advice and support.

The other partners recognized the CHC as an agency with strong community linkages, an excellent record of program management and high community credibility. None of the other partners were positioned to be able to take the leadership needed to make the program a success.

The benefits for the clients come from building social support networks, education, health services, personal health practices and coping skills, and social and physical environments. A strong evaluation component is built into the program and should help guide other community-based mental health initiatives.

6. Building Employment Skills among Youth at Risk – Somerset West CHC

Somerset West CHC is in an older urban neighbourhood of Ottawa. The CHC had been concerned about the number of high-risk youth who were unemployed and facing barriers to education and employment services. When the federal government withdrew its mandate for training programs, access to youth employment services threatened to disappear altogether. The CHC decided to capitalize on the presence of a vibrant high tech industry in the city, and to bring key partners together to deal with the problem.

The CHC convened representatives of the municipal, provincial and federal governments, Youth Services Bureau (an agency supporting at risk youth), the school boards, the local university and community college and 32 medium and small high tech companies. CHC staff convinced the partners to participate in a Youth Employment Apprenticeship Program which combines technology and computer skills training with life skills training over 14 weeks, followed by 14 weeks of work placement. Funds were secured from the city government and the Ministry of Colleges and Universities, while local partners contributed their help in curriculum development, educational upgrading and work placements. After 3 years, 99 youth have gone through the program and 85% are either employed or pursuing higher education. Follow-up testing has shown that their health and self-esteem has increased, their housing has stabilized and they have reduced their use of alcohol and drugs.

The program addresses income and social status, employment, social support networks, physical and social environments, personal health practices and coping skills, education and health services. The CHC is the key player that brought together all the necessary partners, coordinated the strategic development of the program, and secured the funds. The CHC manages the program, providing staff and in-kind support as well as follow-up evaluation with the program graduates.

7. Supporting High-Risk Youth in Rural Ontario – North Lanark CHC

Many young people in this rural community were dropping out of school and getting in trouble because of having nothing to do. Many students were identified as having learning disabilities; poverty and social and geographic isolation faced many others. The CHC Community Developer identified the problem and brought together representatives from the local schools, a child and youth mental health agency, and an existing school-based nutrition program. The CHC and its partners secured project funds from several foundations as well as the National Child Benefit. A multi-faceted program was launched, comprising recreation programs, a drop-in with a nurse practitioner and social worker on site, psychosocial support groups in the schools, transition programs for students moving into high school, and an extended school snack program. Young people were also encouraged to take leadership in the community, and developed a skateboard park in the village. Between 50 and 80 young people take part in these programs on an annual basis. Youth in crisis are now more comfortable seeking help at the CHC and the schools are beginning to take over some aspects of the program for the longer term.

The determinants of health at issue in this program are healthy child development, social support networks, education, personal health practices and coping skills, health services and social environments.

The CHC was the driving force behind the program. While the other partners were well aware of the problem, they did not have the community development resources to do the organizational work that made the program a success. As well as providing programs for young people, the initiative has given them an opportunity to develop leadership skills that are being acknowledged by the community and helping to create a more "youth-friendly" environment.

8. Building a Network to Counter Elder Abuse – North Kingston CHC

The North Kingston CHC serves the northern part of a small urban centre on Lake Ontario. The CHC and some of its senior clients became concerned about elder abuse. Through the Community Developer, the CHC brought together a local seniors' agency, the public health department, a continuing care centre and the police. They agreed to participate in a network aimed at raising public awareness about elder abuse, and finding ways to reach out to seniors needing advice and support. The CHC secured funds from the city and a local business, and the seniors' centre provides space and in-kind support. The network supports advocacy activities through letters to local newspapers, trains seniors to offer peer support, operates a central telephone and referral service, and sponsors a resource group for seniors where they can get advice and help from a psychologist, a social worker and the police when they need it.

The Elder Abuse Network addresses social support networks, education, social and physical environments, personal health practices and coping skills. The CHC is the "glue" that holds the network together.

9. Community Economic Development – Centretown Laundry Co-op – Centretown CHC

Four years ago in Ottawa, poverty groups held Peoples' Hearings to speak about the issues confronting people with low income in the city. The hearings coincided with substantial cuts to welfare rates and services by the provincial government. Two Centretown churches decided to respond by working in partnership with Centretown CHC and low-income and street-cultured community residents to create a laundry co-op. This affordable self-service laundry opened in a local site housing a number of community-based services. People join the co-op by paying the $1.00 membership fee, and then can do their laundry for a fraction of the cost at a commercial laundromat. The churches provide leadership, have legal responsibility for the project, and raise funds while the CHC sits on the governing body, provides office space as well as supervision and administrative support for a coordinator and part-time outreach workers. The CHC also brings its strong linkages with other community agencies to help support the operation of the program and its members. The service has become a meeting ground and confidence-builder for its members, who participate in all aspects of the operation and are becoming more involved in governance. Members are now exploring ways to generate income for themselves by doing laundry for local businesses.

This practical project addresses many of the determinants of health: income and social status, social support networks, employment and working conditions, social environments, personal health practices and coping skills, and culture.

These case studies show the extent to which connection to community drives CHC operations. CHCs build and participate in coalitions, networks and partnerships – sometimes with like-minded agencies and sometimes with otherwise disparate community elements. The focus on the determinants of health and the modus operandi of the CHC instinctively reaches out and draws in partners; CHC staff teams actively look for ways to bring people and organizations together to work on community health issues. They create openings for the voices and strengths of community members to develop the skills and confidence they need to take control of their individual health issues and to take action with their neighbours on collective concerns. The breadth of interest in the determinants of health gives CHCs a platform from which to speak up on social issues that affect the community at large. Their closeness to the grassroots creates trust with community members and gives CHCs a knowledge and understanding of community health that is not always available to more traditional health providers and institutions. The flexibility of the CHC enables it to mediate between these traditional providers and other parts of the community in order to create opportunities for partnerships and cooperative action.

Observations

A. CHCs and Primary Care Reform

As noted earlier, the Ontario Ministry of Health and the Ontario Medical Association have launched Family Health Networks as a means to improve primary health care delivery. So far community health centres have not been involved in the overall initiative. It may well be asked why this is so. On the face of it, the objectives of primary care reform and the CHC model are highly consistent:

- CHCs are accessible geographically, culturally, linguistically and economically. CHCs don't just draw people to them, they also reach out. They are flexible and can respond quickly to changing community needs.

- They provide comprehensive services in urban, rural and remote communities In addition to physicians, nurses and nurse practitioners, they also generally have some staff support for social work, health education, and community development. CHC multidisciplinary teams enable referrals within the centre so client issues can be addressed holistically. The breadth of professional disciplines enables CHCs to create referral networks with other community agencies that can offer more specialized services to their clients.

- CHC clinical services are provided on a 24/7 basis, by their own staff or by sharing on-call with other CHCs in the same area (as the Ottawa Centres do) or by setting up arrangements with other health agencies (such as the university hospital in the case of the North Kingston CHC).

- Collaboration among CHCs, and between CHCs and other health and community partners, brings a range of service to their clients that would not be possible if the centres were each operating separately. Collaboration and partnership mean more effective use of scarce resources – funds, expertise, efforts. There is much less duplication and overlap, and the sum of activity is most often more than its parts – there is a great deal of value added by partnerships that bring resources to bear far more effectively together than if those same resources were used by the partners individually.

- The strong health promotion and education component of CHCs helps people to manage chronic conditions better and increases their understanding of how to stay healthier longer.

- The focus on the determinants of health leads to a strategy of building the capacity of individuals and the community to take charge of their own health individually and collectively. This contributes to a more positive health outcome for individuals and families, and promotes a more active citizenry where people come together to define needs and find solutions at the community level.

- Cost containment is achieved through global budgets, and cost effectiveness in terms of health outcomes for individuals and communities should be the result of primary prevention and health education.

- The accountability framework of CHCs through accreditation and program evaluation ensures the continued clear focus on the fundamentals of wellness, collaborative partnerships, and building individual and community capacity. This means that CHCs remain in and of the voluntary sector and responsible to their communities, as well as to their funders. The framework also provides the means to track health outcomes at both the individual and community levels in order to assure high standards of care and service responsive to community needs.

It is no surprise then that community health centres view their model as a logical part of any primary care reform initiative and, through their provincial association, have tried to press the point on its efficacy. In the fall of 2000, the Minister responded by announcing a Strategic Review to examine the strengths and limitations of CHCs as a means of organizing and delivering primary health services, as well as the opportunities and challenges in using CHCs as a vehicle for delivering on key Ministry strategies. The Strategic Review was completed in the spring 2001 and is now with the Minister's office for consideration. While the report is not yet public, there are expectations that the review will support the CHC model and lead to recognition of its contribution to primary care reform objectives.

In Eastern Ontario, there are two Family Health Networks – one in Kingston that is fully operational and one in the Ottawa area that was still in development at the time of the Ministry's Phase 1 Evaluation in March 2001. There are also 13 community health centres – in urban, suburban and rural communities, including one centre serving the French-speaking population of Cornwall and one serving Aboriginal people living in Ottawa. The proximity of existing CHCs to the Family Health Network pilots presents opportunities for assessing the two models on common ground, and learning more about their respective contributions to improvements in primary health care delivery.

B. Community Health Centres and the Priorities of Canada's First Ministers

The Community Health Centre concept also supports the priorities of Canada's First Ministers. The First Ministers' Action Plan calls for: improved access, strengthened investments in health promotion and wellness, improvements to primary health care through interdisciplinary primary health care teams, and clear accountability and reporting to Canadians. All of these objectives are consistent with the community governance model of the CHC, as well as its fundamental operating principles.

C. Why then are CHCs not one of an array of models being assessed?

Our focus on Ontario in particular points to several possible reasons.

The initiatives for Primary Care Networks and Family Health Networks arose from discussions and negotiations between the Ministry of Health and the Ontario Medical Association. Therefore, the model is physician-centred and seeks to change billing practices from fee-for-service to some form of salary for physicians with capitation payments to the networks. The funds to support the initiative are drawn from the Ontario Health Insurance Plan (OHIP) that presently pays for the vast majority of fee-for-service private practice family physicians. The focus is quite narrow even though it does provide some scope for nurse practitioners and other health professionals.

On the other hand, the CHC Program within the Ministry of Health is separate from the division of the Ministry that deals with physician services. This has been advantageous in many ways because it has enabled CHCs to operate and develop their potential without competing for funds with the OMA. The fact that the Ministry provides ongoing support for more than 50 CHCs across the province indicates their interest and understanding of the benefits of the model. Nevertheless, at $100 million or less than 1% of the Ministry's total budget, total funding for the CHC Program is miniscule.

At a time when governments are trying to control costs and reallocate to more effective service models, the possibility of adding significant new funds to support CHCs in communities that want them is not likely without some kind of reallocation from other Ministry programs. In that event, the CHCs could be seen to be competing for funds earmarked for physician services, among others. It is no secret that organizations representing physicians would not welcome a primary health care model that would move them towards salaried positions as employees in CHCs. This was clearly set out in the report Primary Care and Family Medicine in Canada – A Prescription for Renewal (October 2000), in which the College of Family Physicians of Canada stated that "While the CFPC believes that CHCs will continue to be a model of choice for some physicians and patients, there are too many variables...to presume that a single model will be appropriate for all. We therefore oppose any attempt to force or conscript family doctors into CHC practices. The reality is that in Canada, most family physicians still favour some form of independent private practice and should be supported to carry on in this way".[76] This perception that the CHC may become the single model for primary care reform has perhaps contributed to a situation where the OMA-sponsored Family Health Networks are now being touted as the (only) model, with CHCs somewhat sidelined. It is worth proposing that there is room for both models, and that real or perceived "competition" between the two is not productive for the government, health care providers or the people of Ontario.

There may also be another factor at play. CHCs in most cases cover a geographic catchment area so that anyone who lives within the area can make use of their services. While the programs CHCs provide are broad in scope, they have been especially successful in reaching out to disadvantaged and marginalized populations – rural and

northern communities that are unable to attract private practice physicians, urban Aboriginal people, the homeless, the poor, recent immigrants and refugees. There is now some concern that this success may "pigeonhole" the CHC model as only a service for "hard-to-serve" populations while the physician-based models are directed to the mainstream community. If these concerns were borne out, CHCs would only be seen as a model of primary care in situations where Family Health Networks do not come together. In effect CHCs would be part of the reform almost as a last resort or for marginalized populations only, rather than being integral to the initiative.

Finally there is not enough research and evaluation on how the CHC model makes a difference to its clients and how it contributes to the more effective delivery of primary health care services. This is perhaps a more debilitating problem because it leaves arguments for effectiveness on less than solid ground at a time when evidence of that effectiveness is needed to advance the model of care. An added challenge is that social development/community development has always had difficulty providing quantitative evidence about its effects. Recent efforts to create a program evaluation framework and increasing demands for CHCs to be more accountable for the funds they receive have not yet brought them dedicated funds for evaluation nor the in-house expertise needed to support it. Links to researchers in the academic community are not very strong nor are they widespread across the sector. If CHCs are to be seriously considered as a solution for primary care reform, more attention and effort will be needed on this front as well.

Conclusion: Community Health Centres – The Voluntary Health Sector at Work

The community health centre model as practised in Eastern Ontario is a model of the voluntary health sector at work. Their strategic direction and accountability are grounded in the community. These CHCs originated in people who came together around health issues and needs, and were able to organize their neighbours to build a case for a community health centre. These grassroots volunteer efforts carry over into the governance of an operating CHC, which is a non-profit organization with a board of community volunteers. Through formal bylaws, annual meetings, and regular client and community consultation processes, the community health centre maintains its accountability to its roots and reflects community needs in its programs and services. CHC accountability for public funds is strengthened because they are organized in law as non-profit corporations or registered charities. CHCs in Ontario use volunteers extensively, in board and committee work, program implementation, clerical and administrative support, and in program and volunteer coordination. Through these voluntary organizations, citizens add value through collaborating to meet community needs. Stronger communities and a stronger society are built.

For Further Research

The voluntary sector community health centres that were the subject of this investigation provide important examples of how organizations that are based in and accountable to the community can provide a key public service. The examples outlined above highlight the mix of community development, inter-sectoral action, collaborative mechanisms, and

front-line delivery of primary health care services that takes place through a community-centred organization that builds on determinants of health.

This investigation suggests that further research could improve understanding of the role the voluntary health sector plays in Canada and demonstrate its efficacy as part of the broader health policy debate. Some possible lines of inquiry include:

- Investigation into incentives for collaborative efforts such as those noted in the description above of CHC activities – what encourages, and discourages, collaboration?
- Descriptive research on horizontal collaboration across communities and sectors in health – what conditions in the community and in the individual organizations which facilitate cooperative work? How can such conditions be fostered, and by whom?
- Descriptive research on vertical collaboration between local organizations such as CHCs with regional and national organizations in the voluntary health sector – what examples currently exist, and are there other opportunities around public issues such as primary care reform?
- Investigation into other voluntary organizations that provide public services —Children's Aid Societies in Ontario come to mind, as do hospitals and universities. How do organizations with a publicly assigned mandate balance off accountability for their legislated mandates with their voluntary structure?
- Examination of how CHCs and other voluntary sector health agencies make a difference for individual and community health, and how they contribute to the health system as a whole. How do these models contribute to the objectives of a more accessible, responsive health delivery system that helps people and communities live healthier lives? What place should these models have in improving primary health care?

ANNEX A

COMMUNITY HEALTH CENTRES – EASTERN ONTARIO

CENTRE	POPULATION SERVED	NUMBER OF CLIENTS	NUMBER OF STAFF	BUDGET	FUNDERS

CARLINGTON Centre + 4 satellites	• # catchment: 55,000
	• older suburban area
	• special populations
	  • low income
	  • families/teens
	  • multiethnic population
	  • people with severe mental illness
		8,000	70	$ 3.8 M	Ontario Government (55%)
					Federal Government (3%)
					Ottawa Hospital (25%)
					City of Ottawa (12%)
					Other (5%)

CENTRETOWN	• # catchment: 44,000
	• urban core/some city-wide
	• special populations
	  • elderly
	  • low income families
	  • homeless
	  • single, low income
		12,000	83	$4.8 M	Ontario Government (94%)
					City of Ottawa (5%)
					Other (1%)

SANDY HILL Centre + 1 satellite + 1 off-site program +1 off-site point of service	• # catchment: 22,000 • urban core/some city-wide • special populations • elderly • homeless • low income • francophone • new immigrants	17,000	80 permanent 64 contract	$ 7.4 M	Ontario Government (91%) Federal Government (1%) City of Ottawa (< 1%) Other (7%)

CENTRE	POPULATION SERVED	NUMBER OF CLIENTS	NUMBER OF STAFF	BUDGET	FUNDERS

SOUTH EAST OTTAWA
Centre + 1 satellite
(28 points of service)
	• # catchment: 78,000
	• suburban
	• special populations
	  • low income families
	  • new Canadians
	  • seniors/disabled persons
	  • youth
	  • vulnerable populations
		9,730	72	$ 5.6 M	Ontario Government (85%)
					Federal Government (1%)
					City of Ottawa (10%)
					Other (4%)

PINECREST - QUEENSWAY	• # catchment: 49,000
	• suburban
	• special populations
	  • children, youth and families (esp. single parents)
	  • low income households
	  • immigrants and new Canadians
	  • seniors living alone
	  • people with severe mental illness
	  • people with disabilities
		13,000	120	$7.7 M	Ontario Government (81%)
					Federal Government (4%)
					City of Ottawa (11%)
					Other (4%)

L'ESTRIE	• # catchment: 76,800 • small city and several small surrounding communities • francophone residents of Eastern Ontario • rural and underserviced	9,000	40	$ 3.0 M	Ontario Government (99%) Other (1%)

CENTRE	POPULATION SERVED	NUMBER OF CLIENTS	NUMBER OF STAFF	BUDGET	FUNDERS
NORTH KINGSTON	• # catchment: 25,000 • small city • special populations ▪ elderly ▪ low income families ▪ youth	4,000	43	$ 1.9 M	Ontario Government (99.9%)
SOMERSET WEST	• # catchment: 38,000 • central west • special populations ▪ Asian community ▪ Youth ▪ Seniors ▪ Low income single parents	13,000	88	$5 M	Ontario Government (82%) City of Ottawa (15%) Foundations (3%)
MERRICKVILLE AND DISTRICT	• # catchment: 15,000 • village and rural area • special populations ▪ elderly ▪ families with children	3,000	10	$1 M	Ontario Government (100%)
WABANO	• urban/Aboriginal community • estimated population: 30,000	2,500	23	$1.2 M	Ontario Government (Aboriginal Health and Wellness Strategy) Aboriginal Healing Foundation Health Canada United Way City of Ottawa (from HRDC)

ANNEX B

SUMMARY ALL CENTRES

	North Lanark	Carlington	Somerset West	CCHC	North Kingston	Wabano	Sandy Hill	Merrick-ville
CHC Type								
- Urban		X	X	X	X	X	X	
- Rural	X							X
- Other						Aboriginal		
Partnership								
- Health Promotion	X	X	X	X	X	X	X	X
- Early Intervention	X	X	X	X	X	X	X	X
- Chronic	X	X	X	X	X	X	X	X
- Social Action	X	X	X	X	X	X	X	
- Community Building	X	X	X	X	X	X	X	X
- Literacy		X						
Target Pop.								
- <6 years	X	X	X	X	X	X	X	X
- Children	X	X	X	X	X	X	X	X
- Teens	X	X	X	X	X	X	X	X
- Adults		X	X	X		X	X	X
- Seniors	X		X	X	X	X	X	X
- GLBT				X		X		
- Ethnocultural		X	X	X			X	
- PWD	X	X						X
- Aboriginal				X		X	X	

	North Lanark	Carlington	Somerset West	CCHC	North Kingston	Wabano	Sandy Hill	Merrick-ville
- Francophones		X		X			X	
- Rural	X							X
- Abused Women		X						
- Under/ Unemployed		X		X				
Partners								
- Hospitals		X	X	X	X	X	X	X
- Public Health	X	X	X	X	X	X	X	X
- Other Health Centres/agency	X	X	X	X	X	X	X	X
- Schools	X	X	X	X	X	X	X	X
- Social Agencies	X	X	X	X	X	X	X	X
- Churches	X	X	X	X	X		X	
- Community Agencies		X	X	X	X	X	X	X
- Businesses		X	X		X		X	X
- Private Practice						X	X	X
- Municipal	X		X	X	X			X
- Provincial			X					
- Federal			X	X				
- Housing Agencies	X			X			X	

	North Lanark	Carlington	Somerset West	CCHC	North Kingston	Wabano	Sandy Hill	Merrick-ville
- University		X	X	X	X		X	
- Aborig orgns						X		
- Police								
- Occup Health Profs							X	
- Community network (business, council, service clubs)								X

	North Lanark	Carlington	Somerset West	CCHC	North Kingston	Wabano	Sandy Hill	Merrick-ville
Partner Roles								
- Co-loc	X	X	X	X	X	X	X	X
- Co-sponsors	X	X	X	X		X	X	X
- Advisory	X	X	X	X	X	X	X	X
- Funding	X	X	X	X	X	X	X	X
- In Kind	X	X	X	X	X	X	X	X
- Volunteers		X	X	X		X	X	
- Staff		X	X	X	ON CALL		X	
CHC Role								
- Management/ Coordination	X	X	X	X	X	X	X	X
- Advisory	X	X	X	X	X	X	X	X
- Co-sponsors	X		X	X	X	X	X	X
- Funding		X	X	small	small	Small		Flow through
- Staff	X	X	X	X	X	X	X	X
- Volunteers	X	X	X	X	X	X	X	X
- In Kind	X	X		X	X	X	X	X
Education of mainstream agencies						X		

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Toward Understanding the Role and Contributions of the Voluntary Health Sector Within the Health System: An Organizational Focus

Prepared for Voluntary Sector and Strategic Frameworks Unit
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November 2001

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The opinions expressed in this paper reflect the views of the author and do not necessarily reflect those of Health Canada or the Government of Canada.

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Toward Understanding the Role and Contributions of the Voluntary Health Sector Within the Health System: An Organizational Focus

INTRODUCTION

For the past 10 years, Canada has been undergoing fundamental reform in the health care sector. Often this involves structural change where publicly funded health related services are amalgamated into a regional governance structure. Services and activities of the voluntary health sector (VHS) have not been formally part of this reform, but are inevitably involved as the public system strives to achieve more effective and integrated delivery of services. It is important to understand the role and contribution of the VHS as health reform has been characterized by reduced levels of funding and the VHS has often been implicated as "part of the solution" (Gibelman and Kraft 1996; Steuerle and Hodginson 1998; Blackshaw 1995).

This paper reflects an exploratory effort to begin to outline a conceptual approach to understanding the role and contribution of the VHS in service delivery across the spectrum of health services from health promotion and wellness through to palliative care. This conceptual approach has been informed by published literature as well as examination of annual reports of 20 national organizations in the VHS in Canada. The paper sets out research directions which will assist in further efforts to describe and better understand the contribution of the VHS, and will thus inform future intersectoral initiatives. Because primary health care and rural health are of particular interest in Canada at the present time, focused attention is paid to these dimensions where possible.

THE NATURE AND SCOPE OF THE CURRENT INVESTIGATION

Adequate health care is highly valued by the Canadian public. Recently, however, due primarily to funding reductions, this health system has come under some criticism. Although the VHS has a long-standing history in Canada, less is known about it as, until recently, the sector was comprised of many organizations operating at varying levels (local, provincial and national) but quite independently, often each targeting one specific health issue. Recently health charities have formed the Health Charities Council of Canada with a view to bringing their collective influence to bear on issues of shared interests such as strengthening the health system and increasing the VHS's ability to monitor and influence public policy. As the health system is a highly valued component of Canadian society, and one in a state of great flux and examination, it seems useful to examine the way in which the voluntary sector is involved, and contributes to, the health of Canadians. This is particularly so if one considers that Canadians express a much higher level of credibility and support for voluntary sector organizations than any other public institutions (Reed and Selbee 2000). The focus in this paper is on the nature and

range of organizational relationships through which the VHS interacts with, and influences, the formal health system (FHS).

The work described in this report focuses attention on a very specific subset of the universe of possible ways to think about the VHS and its role within the health system. Each of the words in the title of this paper, taken singly, could result in a substantive discussion about what it means and encompasses: voluntary, health, sector, health system, role and contribution. Voluntary can refer to informal helping such as occurs when a neighbour is elderly and frail, as well as more formalized efforts through charitable or nonprofit organizations or through volunteer efforts within an organization that is part of the publicly funded health system, such as a hospital. Much of our knowledge to date about voluntary efforts is based on survey data, which collects information from individuals. The recent National Survey on Giving, Volunteering and Participating done in Canada is a notable example (Hall et al 2001). Health is sometimes taken to refer only to those activities which have improving health as their explicit and near term objective; other times it refers to activities which can reasonably be seen to impact health through more indirect means e.g. anti-poverty and employment initiatives. Often a distinction is made between voluntary organizations and nonprofit organizations generally, with the former containing a significant degree of unpaid human resource contribution. The focus in this paper is an organizational one. That is, the area of interest is those entities within society which are formally constituted as organized enterprises for the purposes of contributing to improved health of Canadians in some way. Conceptually, the view is taken that voluntary organizations with an interest in health may be considered de facto part of the health system. The question of interest in the current work is to begin to build an understanding of the mechanisms through which voluntary organizations make a difference within the health system in Canada. The focus on organizations and their mechanisms of impact (as opposed to individuals who volunteer to improve the health of Canadians) is a unique and specific focus.

The Voluntary Health Sector

There has been much discussion about what exactly constitutes a 'voluntary' sector (Wardell et al 2000, Anthony and Young 1990; Dreessen and Reed 2000). For the purposes of the present work, a recent Canadian report provides a suitable characterization of nonprofit/voluntary organizations (Febbraro et al 1999). Febbraro and colleagues suggest that the operational definition provided by Salamon and Anheier (1997) is appropriate and that definition is used here. It defines nonprofit/voluntary organizations as those that are 1) organized, 2) private, 3) self-governing, 4) nonprofit distributing, and 5) voluntary. Conceptually then, organizations that are formally constituted to some degree, are separate from government, are equipped to control their own activities, do not distribute profits to owners or directors, and involve some degree of volunteer participation are considered within the realm of the 'voluntary sector' for purposes of this paper. This definition does not address the issue of public benefit versus member benefit. Conceptually at least, organizations created for the public good as well as those created for the benefit of those who belong to the organization, would be

considered in this present work, as long as the intended impact of their actions was health related.

It has been suggested that volunteerism can best be described as a continuum (Wardell et al 2000), and perhaps the same could be said for voluntary organizations. An organization such as the Canadian Cancer Society, which is the largest health charity in Canada (based on revenue), is clearly a voluntary organization according to the above definition – it is funded totally by donations from the public, and its volunteers outnumber staff by a ratio of 500 to 1. On the other hand, hospital foundations which have become increasingly numerous and active in the recent past have many of the same characteristics. One exception is that their ability to control their own activities is less clear, as often they have been created explicitly by a government-funded hospital to raise funds for hospital-related purposes. There is a degree of coupling inherent in these relationships, which is not the case in all voluntary organizations.

There is scant descriptive information about the population of organizations in the VHS. Although acknowledging quite good information about volunteering in Canada from an individual perspective, Dreessen and Reed (2000, p. 48) state: "We are completely in the dark about even the basics of the overall situation: how many organizations there are in the sector, what their resources are, how many people they employ, what economic and social value-added they provide, etc." While they were speaking of the sector as a whole, and not just the health sector, the same shortcomings apply. The focus in this report is to examine the nature of relationships between organizations in the VHS and the FHS, while acknowledging that our knowledge about the population of organizations in the VHS is limited.

The Formal Health System and Two Special Cases

The term 'formal health system' (FHS) has been used here to collectively describe those organizations of interest with whom voluntary organizations may interact for the general purpose of influencing health. Canada's health care system is a complex arrangement between the federal and provincial governments, knit together by legislation (in particular the Canada Health Act) and shared funding. Health services are provided for the most part through a publicly funded health system within which health-related programs and services are provided by both public (e.g. hospitals and health regions) and private institutions (e.g. physician services, private long-term care facilities). This is the most common characterization of how health services are delivered in Canada (Klatt 2000). Rarely is the nonprofit or voluntary sector even mentioned. However, recent analysis of Canadian data suggests that there are more hours of personnel time contributed in the interests of health by volunteers (formal and informal volunteering) than there are by paid staff within the health industry (Carr 2001). It is timely to do more research to try to increase our understanding of voluntary contributions to the system.

There are two components of the FHS with which voluntary organizations interact: the various levels of government and organizations involved in delivering health-related programs and services. Although there is also discussion about what type of organizations should be included within the 'health' voluntary sector which hinge on the perception of 'health,' this dimension has received little attention in this report. Since the focus is on examining transactions and relationships between organizations, and the literature is limited, no restrictive definition of health has been invoked. Leaning toward a population health approach, literature referring to an interaction which includes an organization that is directly or indirectly related to influencing health is considered of interest.

Primary (Health) Care

Primary health care has received significant attention in recent public discussions in Canada. Primary care was identified by the Forum on Health as one priority area requiring attention in efforts to create a more integrated system that funds care, rather than providers or sites of care (National Forum on Health 1998). Other areas identified included pharmacare and home care. Primary care was defined by the Forum as 'the care provided at the first level of contact with the health care system – the point at which health services are mobilized and coordinated to promote health, prevent illness, care for common illness and manage ongoing health problems' (p. 22). Although this seems somewhat consistent with the community-oriented primary health care definition as coined by WHO at Alma Ata in 1978, in fact much of the attention in the Canadian context has been focused on those primary services which are delivered by physicians (Hutchison et al 2001).

Rural Health Care

Rural health and health care has been a recent focus in Canada as evidenced by the establishment in 1998 of the Office of Rural Health within Health Canada. Overall health status tends to be lower in northern rural regions compared with other locations. Shorter life expectancies, increased prevalence of chronic diseases (e.g. tuberculosis, Parkinson's disease, obesity, multiple sclerosis, type 2 diabetes, drug and alcohol abuse) and long-term disabilities and greater limitations on activity levels are reported. (Bradshaw and Casebeer 2001). There is no definitional clarity in the literature with respect to the meaning of 'rural.' In a recent literature review done in Alberta, the terms northern, rural and remote were used as a collective phrase, as the terms are often used interchangeably in the literature or are used specifically but often refer to the same milieu. The majority of the published health literature refers to 'rural' without any qualification or definition beyond an assumption of non-urban. This is a definition of exclusion rather than an explanation of difference or unique attributes (Troughton 1999; Bradshaw and Casebeer 2001). Intuitively, it seems as though voluntary health organizations (or at least voluntary helping) may be more important in rural and remote settings.

METHODS USED IN THIS RESEARCH

This project involved two components: a literature search and a content analysis of annual reports of national health charities. A convenience sample of 17 health charities that are members of the recently formed Health Charities Council of Canada were chosen and their annual reports analyzed to determine how the organizations described their interactions (directly or indirectly) with the FHS. The second component involves a literature search of seven relevant databases (Proquest, Medline, Health Star, Sociological Abstracts, Social Work Abstracts, Academic Search Premier). This was done to identify articles which include a description or analysis of relationships between organizations in the health voluntary sector, and one or more in the FHS (including government, health regions, hospitals, primary health care providers, community agencies, etc). A brief description of the approach to literature searching is included in Appendix 1. In addition, selected unpublished literature and personal contacts were used to provide illustrative Canadian vignettes. A group of researchers and practitioners reviewed the summary of findings from the literature and annual reports and made suggestions with respect to a conceptual approach to increasing our knowledge of organizational interactions between the VHS and the FHS. Results from the review of annual reports is presented first, followed by findings from the literature, followed by a discussion of conceptual frameworks, and finally suggestions for further research.

THE INTERACTION AS PORTRAYED IN ANNUAL REPORTS OF VOLUNTARY HEALTH ORGANIZATIONS

Annual reports from the most recent year available from 17 Canadian health charities were reviewed. The sample was a convenience sample (based on speed of response to requests for copies of annual reports) chosen from the members of the Health Charities Council of Canada whose annual revenues ranged from $240,000 to over $100 million. Those organizations whose annual reports were examined are listed in Table 1.

There is remarkable congruence among what these organizations report as their areas of activities: education, patient (or client) services, advocacy and in most cases, research. In addition there are some themes that predominate in the annual reports. Many of the organizations are undergoing some sort of structural revision or renewal, revenues are stable or increasing, partnerships were common, and some important events in the external environment such as the creation of the Canadian Institutes for Health Research and the action of the Government with respect to granting of disability tax credits to individuals with certain diagnoses, were influencing activities. Partnerships were mentioned by many of the organizations, although this often referred to joint activities with other components of their own organizations (especially in those which do not have a corporate structure, but rather an association or federative nature) and often also with other charities or nonprofit organizations. Several organizations are involved with other organizations in working toward some sort of national level strategy to address issues related to the specific disease.

Table 1. Health Voluntary Organizations

Alzheimer Society of Canada
Arthritis Society
Asthma Society of Canada
Canadian Cancer Society
Canadian Cystic Fibrosis Foundation
Canadian Diabetes Association
Canadian Lung Association
Canadian Mental Health Association
Canadian Palliative Care Association
Canadian Paraplegic Association
The Huntington Society of Canada
Lupus Canada
Multiple Sclerosis Society of Canada
Muscular Dystrophy Association of Canada
The Parkinson Foundation of Canada
Spina Bifida and Hydrocephalus Association of Canada
Thyroid Foundation of Canada

The purpose of the current analysis was to ascertain how these health charities described their interaction and relationships with organizations in the FHS, which in this case is meant to include policy making bodies and those organizations that deliver health related programs and services to Canadians.

Because annual reports are typically quite brief, and organizations try to provide high-level information on many topics, there is understandably limited detail within the annual reports with respect to interactions with other parts of the health system. Appendix 1 includes excerpts from annual reports which seem to reflect some direct interaction with the FHS. Because of the brevity of information, the 'raw data' are presented so that the reader may critique the inferences made here. The comments extracted refer to some aspect of the charitable activity which was undertaken to address the mission of the organization. Although several of the organizations clearly had a relationship with Health Canada in that they received funds from that organization, these relationships which referred to funding sources for the charity are not included in the table i.e. the activities noted had to do with the 'outputs' of the voluntary organizations, rather than the 'inputs.'

The nature of the implied relationships between voluntary organizations and those in the FHS included examples of direct funding, collaborative activities for specific purposes, contracted services by the voluntary organization and in one case the health charity paid to have an expert panel go in and review the unit providing care for the disease they were interested in, with a view to assessing quality of care. Direct funding for clinical personnel is provided by organizations focused on Parkinson's disease, muscular dystrophy, and cystic fibrosis. In addition, there was at least one example of advocacy, where there was an attempt to influence another organization's activities through arm's-length interaction.

Understandably perhaps, as these reports emanated from the national level of these organizations, there was not a great deal of reference to community-level activities. There was no direct mention found of community-level interactions with health service organizations. However, if one assumes a broad 'determinants of health' framework, in one case (Canadian Mental Health Association), a program was described that strengthened community partnerships with a view to expanding job creation strategies. Presumably this partnership involved community organizations and businesses generally, and not health service organizations specifically.

The various types of relationships between voluntary health organizations and the FHS, as depicted in annual reports, is presented schematically in Figure 1. Each example of an interaction between the VHS and FHS that was referred to in the annual reports is represented by a number within a different shape. The shapes represent different types of interactions, and the location within the diagram shows the location of the interaction within the progressive trajectory of an illness. The specific details of the interaction can be found in Appendix 1 as identified by the number.

Figure 1
Location of Intended Impact of Interorganizational Activity

LEGEND

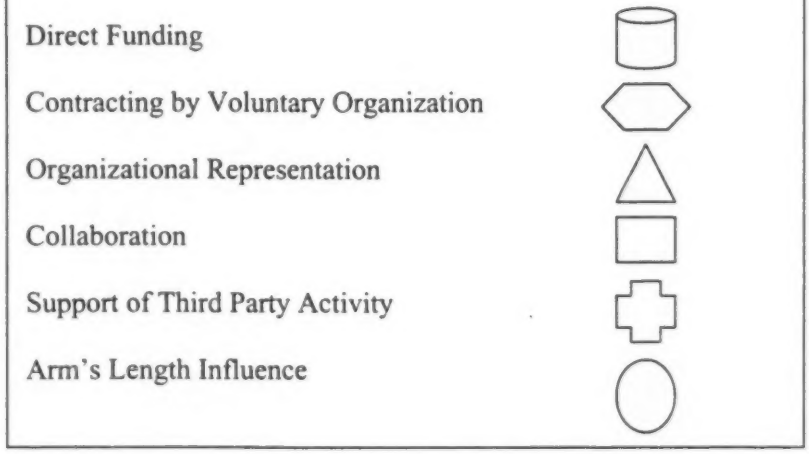
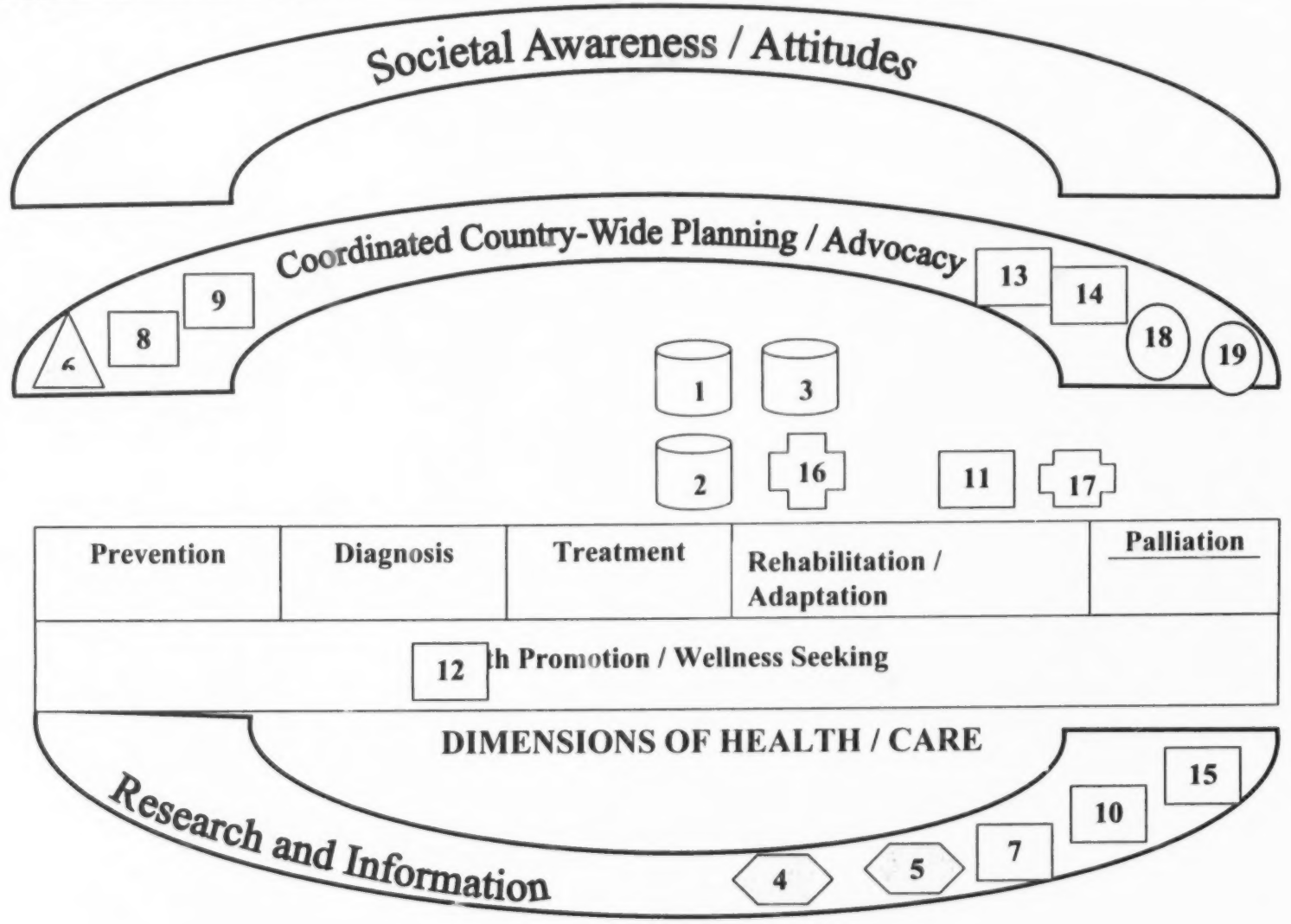


Figure 1 appears on the following page.

Figure 1: Location of Intended Impact of Interorganizational Activity



The excerpts in Appendix 1 imply some direct interaction or influence attempts with organizations in the FHS. There were also comments relating to activities of health charities which would suggest indirect influence on organizations within the health system. These comments are provided in Appendix 2. Health professionals, broadly speaking, are a target of these health charities. In some cases, the charitable organization reported hiring more professionals and although it is not possible to determine from the information provided, this could be seen as a duplication or substitution for services provided within the formal system (i.e. the 'system' has failed). But often the voluntary organizations seek to work with, or influence health professionals, both as individuals such as when information is supplied through Huntington's Resource Centres (where they had two thirds as many contacts with professionals as with patients and families), or through professional organizations. The Canadian Mental Health Association works with the Canadian Psychiatric Association and the Canadian Cancer Society works with the Canadian Dermatology Association. Both of these 'partner' organizations of course, could be conceived as nonprofit organizations themselves, albeit with more of a 'member service' frame than a public service one. They are also both a direct link to the primary health care system.

Discussion

Generally speaking, there is very little evidence arising from the national level annual reports of health voluntary organizations that reflect interorganizational relationships with service delivery organizations at the community level, other than perhaps through the direct funding of clinical personnel in specialized areas. Often voluntary organizations are thought to be particularly relevant in communities, and lack of evidence from this particular source should not be interpreted as no relevance or action by health voluntary organizations in Canadian communities. As the programs and activities reported in these annual reports are countrywide in nature, one might assume that they are in place because a general sense of need has arisen from many communities across the country. It is important to remember that the annual reports examined in this report were from the national level of organizations. In most cases, there are other levels as well (community, regional or provincial). Therefore, the nature of the information included in these annual reports is fairly general. One should not assume that these reports reflect the total interactions among the voluntary health organization in question and various components of the health system. It was a convenience sample, and observations made here serve only as a beginning exploration of the nature and range of relationships and interactions between organizations in the voluntary sector and the FHS.

Some of the observations suggested by this review of annual reports are similar to findings in a study of voluntary organizations in Ontario (Howe and Reed 1999). They also noted that organizational restructuring and a move to a more professionally oriented approach were observed in voluntary (not limited to health) organizations. They noted that in the Ontario voluntary sector there is another source of pressure on these organizations: funding is increasingly obtained through contracts to provide services, mostly by governments, and less from grants and from the general public. This move to

contracting was not predominant in the annual reports reviewed, with the possible exception of the creation and maintenance of the Canada Health Network, within which segments of information provision have been contracted to health charities. Perhaps health is different than other areas of human service provision due to the extreme size and resources available within the health system.

THE INTERACTION AS PORTRAYED IN THE LITERATURE

The purpose of this literature review is to glean a sense of the range and nature of interactions between organizations in the VHS and the rest of the health system. This assumes that voluntary organizations can be legitimately considered as part of the health system, perhaps an assumption that should not go unquestioned. If one assumes that the health system consists of a wide range of inputs, various processes which result in a wide range of outputs which ultimately affect health outcomes, the argument could probably be made that voluntary organizations are part of the health system. This is rarely if ever represented as the case in Canada, at least insofar as overviews of the health system are concerned. If one considers the amount of dollars involved, this is perhaps understandable. In the recently published *Health Care in Canada* (Canadian Institute of Health Information 2001) which provides a portrait of Canada's health care system, there is information provided about the amount of money which is donated to health charities in Canada. In 1996, Canadians donated a total of $773 million to charitable health organizations. This is an insignificant amount of money when compared to the amount spent from tax dollars to support health related programs. In 2000, this amounted to $67.6 billion. However, these metrics do not reflect in any way the manpower which is inherent within the voluntary health system. Recent analysis from the 2000 Survey on Giving, Volunteering and Participating and Labour Force Survey done by Statistics Canada suggests that the total hours contributed by volunteer staff may actually exceed that of paid staff within the publicly funded system[1] (Carr 2001). If this is the case, it reflects potentially a much greater contribution to health outputs than is reflected merely by considering the money donated to health charities.

The above refers to the instrumental contribution that voluntary organizations may make in the health care system. They are not usually considered primarily as within the 'health care system', but more so within the voluntary sector. At some point, it will be important to consider the implications of framing voluntary health organizations within the health system, without carefully considering the societal and historical context within which voluntary organizations are traditionally viewed. If one were simply to focus on voluntary health organizations as one more mechanism through which to address some of the myriad of needs that exist within the FHS, it would ignore some of the broader issues involved in the maintenance of a civil society and the role that voluntarism plays therein.

[1] It should be noted however, that this total includes ALL volunteer hours, and not just those contributed within the context of organizations within the voluntary sector. It would include, for example, hours contributed by hospital volunteers.

This work represents an exploratory effort to identify relevant literature with a view to helping to build a conceptual framework which would help one to view, and eventually to understand, the role and contributions of the VHS to health outcomes in Canada. The locale of interest is primarily Canada. This is so because the regulatory and cultural profiles are somewhat unique compared to many other countries. Much of the published literature that refers to the voluntary sector (not necessarily health) comes from the United States or the United Kingdom. Both those countries have contextual and regulatory environments (related to both health care and the voluntary sector) that are different enough from Canada to make findings from research in those two settings somewhat difficult to interpret within the Canadian context. Nevertheless, the research is of some interest, and this review has not been limited to Canadian publications.

The literature which was accessed for purposes of this review include articles related to interorganizational relationships, the role of the voluntary sector in society, interactions between the voluntary sector and government, voluntary organizations and rural health and primary health care.

Interorganizational Relationships

From one perspective, interactions between voluntary organizations and other health-related organizations can be perceived as interorganizational relationships (IOR) and there has been considerable research done in this area. There has been focus both on structural aspects of these IOR (Alter and Hage 1993; Oliver 1990; Borys and Jemison 1989) as well as process issues (Wood and Gray 1991; Alter and Hage 1993; Ring and Van de Ven 1994). Those focusing on structure have identified a range of possible forms that IOR may take such as mergers and acquisitions at one end of the scale where two organizations fuse to form one, to joint ventures, contracts and supplier arrangements which are typified by transactions among autonomous organizations for specific purposes (Borys and Jemison 1989). Dimensions which have been identified as important in shaping the nature of these IORs include things such as the need for the IOR, the symmetry (or lack thereof) of the organizations involved, efficiency, stability and legitimacy (Oliver 1990). Those authors who examine the processes within IORs (as contrasted with the structure) have focused more on the context of the relationship and activities that take place within the IOR (Wood and Gray 1991).

Perhaps one of the most helpful analyses from the perspective of interactions between the VHS and FHS is the work done by Alter and Hage (1993) who studied 15 human service delivery systems in two counties in the US. They examined both the structure and process of IOR within these systems. In a general sense, they were trying to identify factors that may predict the nature and extent of collaboration among organizations. They suggest that IO forms can be organized along three dimensions, which vary between relatively simple to complex: competitive versus symbiotic, numbers of organizations involved, and level of cooperation. The networks that they were examining were of the most complex variety, e.g. many organizations, multidimensional cooperation. They identified several factors that seem to be important to the functioning

of the network. These included the degree to which the network relied upon a single source for resources, the degree to which a network is self-governing, and the degree to which inputs are mandated, rather than voluntary and several variables related to the substantive 'work' that they were trying to accomplish through IOR (the scope of the task, uncertainty, intensity, duration and volume). Both Alter and Hage and Ring and Van de Ven (1994) emphasized the evolving and progressive nature of IOR; that is, there are stages in the development of this type of relationships, and later stages to some extent depend on earlier phases.

The Role of the Voluntary Sector in Society

There have been many who have commented on the role of the voluntary sector in society. The reflections on this can be grouped into two general types: those that refer to the role of the voluntary sector vis-à-vis government, and those that refer more to the type of actions that voluntary organizations undertake in the accomplishment of their missions. Several authors describe the general role of voluntary organizations as being complementary, supplementary or adversarial in relation to government (Young as quoted in Steuerle and Hodginson 1998). Complementary roles are those which add value to publicly offered programs; one way of describing a system in which voluntaries play this role is a horizontally integrated system. When the role is described as supplementary, the implication is that the voluntary organization is providing a service where the public system has failed, and where gaps need to be filled (Middleton 1999; Bukurura 1996). The third general type of relation with government is adversarial. Advocacy is a well known role of the voluntary sector (Craig and Manthorpe 1999; Laws 1997; Brenton 1985).

The second type of role description refers more to the nature of activities that a voluntary organization actually does. These activities can be described as the following, based on what was observed in the literature: a mediating/linking role, direct service provision, and support of citizen involvement. Perhaps the most prevalent theme in the literature relates to the intermediary function that many feel the voluntary sector fulfills. This has been described variously as having a coordinating function (Brenton 1985), a mediating structure, (as between an individual and bureaucracy) (Dobrof 1998), linking between political and civic spheres (Achenbaum 2000), bridging between macro and micro levels (Hunter 1992), and case coordination (Provan & Sebastian 1998). A specific example of this, which is perhaps a separate item but which in a way relates to the bridging of the professional/lay divide, relates to what Dobrof (1998) calls the 'democratization of health information.' This is a relatively recent phenomenon made possible by the explosion of internet use in the recent past. Some frame this as creating another challenge to gatekeeping by dominant medical groups (Fox 2001); others see it as an opportunity for enhancing primary care and self care. Voluntary organizations are well positioned to use their resources to support Internet sites to provide broader access to health information.
Direct service provision is clearly a large part of the role of voluntary organizations, whether that be through a contracting mechanism or through independent programs (Middleton 1999, Laws 1997, Brenton 1985, Sherwood and Lewis 2000).

The third role which some assert the voluntary sector plays is that of providing a vehicle for expression of altruism and citizen involvement (Laws 1997, Dobrof 1998). Regardless of the focus of volunteer work, some feel that the drive to contribute and do something worthwhile is a basic human need (Dobrof 1998). This relates more to a supply-side role, as compared to a demand-side role. It does suggest, however, that one cannot examine only the output side of a system which involves volunteers who are meeting some of their own needs (which may be unrelated to the mission of the voluntary organization) through a particular voluntary organization.

In a related vein, several authors have referred to special attributes that organizations in the voluntary sector have which give them an advantage when tackling certain kinds of issues. The attribute that is most often described is that of being flexible and innovative. Many see voluntary organizations as having an enhanced ability to respond quickly to changed circumstances, or respond effectively to situations where one or more groups are marginalized (Sennayake 1994; Craig and Manthorpe 1999). Billis and Glennerster (1998) suggest a slight modification of this theme, when they assert that voluntary sector organizations have an advantage over organizations in other sectors when it comes to addressing certain types of needs. They argue that certain combinations of disadvantages (financial, personal, societal, community) in groups within society provide a milieu in which organizational characteristics of voluntary agencies have a comparative advantage in addressing these needs. The very complexity and ambiguity that often characterize voluntary agencies provide a unique opportunity to address these issues through voluntary structures, which are often more fluid in their structure and processes.

Interactions Between Voluntary Sector and Formal Health System

This includes interactions with the government and with agencies which deliver health services (including those in rural areas and in primary care settings).

Voluntary Sector/Government Relations

Most of the literature located which specifically addressed relations between voluntary or nonprofit organizations and other entities discussed VHS – government relations (Birdsell et al 1992; Boris and Steuerle 1999; Cobble 1999; Coston 1998; Brenton 1985; Lowenberg 1992). The impact of the policy environment within which voluntary organizations exist is of course important in shaping the context. With respect to published literature, this is very true, as dominant themes arising from different policy contexts reflect very different points of discussion and debate. For example, in the United Kingdom where the National Health Service underwent major reform in 1990, there has been much attention paid to the impact of the purchase/supplier arrangements which were introduced within the National Health Service (Ogden 1994, Craig & Manthorpe 1999). This has created an environment where the opportunities for voluntary organizations to provide certain health and social services under contract to a health authority have increased exponentially. Ferris and Grady (1999) on the other hand speak

to the situation in the United States where hospitals run by charitable organizations are still a large part of the mix of organizations providing health services.

Despite the differences in policy environments and the particular mix of services and financing arrangements for health care, at a high level it is fair to describe general roles of the nonprofit sector in relation to government as being supplementary, complementary or adversarial (Young 1999). In a study of two industries, Kapur and Weisbrod (2000) found considerably different behaviour between government and nonprofit agencies providing similar services. Their research examines organization-level behaviour of agencies providing similar services (homes for the mentally handicapped and nursing homes) within both the government and nonprofit sectors. The authors suggest that, as both these types of organizations are constrained by the fact that they cannot generate profits for shareholders or directors, they should act similarly unless other factors are influencing their behaviour. They used consumer access (as measured by waiting lists) and output quality (measured by patient satisfaction) as indicators of behaviour of the respective organizations. They used data from national surveys done in the US in 1976 and 1987. They found that they did not behave similarly. Government agencies were less likely to have waiting lists, which the authors interpreted as willingness by government agencies to sacrifice quality in order to accommodate more clients. With respect to customer satisfaction, six measures were used. In two of them (overall satisfaction and satisfaction with buildings and grounds) there were no statistically significant differences. However, on the other four measures (rooms and furnishings, staff, social activities) the level of satisfaction was higher for nonprofit institutions than for government facilities in both the nursing home and mentally handicapped facilities. This is interpreted as reflecting the position that governments are suppliers of last resort, and will not turn anyone away, whereas nonprofits, as they are not philosophically or legally obligated to serve all, can limit access to improve quality.

Voluntary Organizations and Primary Health Care

There has been very little research done which examines precisely the role and impact of the VHS within a primary care frame. However, it is clear that voluntary organizations realize the necessity of interacting with primary care providers, be they in prevention-oriented activities, or providing services at the other end of life. The same can be said for primary care providers, who are increasingly commenting on the necessity and desirability of interacting with the voluntary sector, often for the purposes of referring patients to community services (Payne & Clayton 1987; Graham 1995).

There have been two randomized controlled trials done in clinical settings, which have evaluated the impact on patients of having an individual fill a coordinating/linking role between patients and community services. In both these cases, one involving palliative care patients and the other mentally ill patients, patients were randomly assigned to the 'coordination' group or not. There was no clear consensus from these two studies about whether the coordinating role, or the services received in the community (often from voluntary organizations) made a difference. Addington-Hall and colleagues (1992) did not find an overall difference in several measures in patients who were terminally ill who

had been referred to a nurse whose role was to facilitate and coordinate access to community services for those who were dying. The authors attributed this to a lack of fit between the nurse coordinators (who were palliative care experts in their own right) and the skills required for the coordination role. In the other randomized controlled trial, Grant et al (2000) found that patients with psychosocial problems who were assigned to a coordination project which assessed and referred patients to community services (including voluntary organizations) experienced important benefits when compared to the usual care group. They noted, however, that this was at increased cost, and it is not clear whether the difference can be attributed to the services of the voluntary organizations, or to the coordinator herself, as both groups used the same number of community services.

In addition to clinical care, voluntary organizations are active in other areas of primary health care such as palliative care (Robbins et al 1996), health education (Birdsell et al 1992), mental health (Provan & Sebastian 1998) and community health centres (Panet-Raymond 1992).

Voluntary Organizations and Rural Health

Provision of services in rural areas, including health services present particular challenges, but also beneficial aspects that lend themselves to positive action. Although the volume of literature focused specifically on the role of voluntary organizations in rural health care and their interactions with the FHS is limited, there are a small number of studies which address specifically the topic of interest in the current review. Sherwood and Lewis (2000) followed the initiation of several community development initiatives designed to encourage partnerships between local authorities and the voluntary sector to promote programs to assist with transporting those without easy access to medical and social care facilities. These initiatives were created in Britain at a time of decentralization of services and a trend from government (delivery) to (community) governance (Sherwood and Lewis 2000). An initiative based in two smaller communities was created with funding from churches and the local county council with facilitating infrastructure from the local health authority. However, the person power to run and operate the program (coordinators and drivers) were all volunteers. It was not clear if the program is going to be sustained after the initial three-year funding. Several issues were identified during the review. Some of the issues identified within the initial three years were 1) the broadening of the activities beyond 'medical' (typically ride to doctors office) and toward 'health' (ride to visit ill husband, giving child a ride to activities when mother is ill), 2) continued financial commitment of county council as they are relatively uninvolved in service, 3) ability to recruit a new supply of volunteers, given the ages of initial group, and 4) concern that service is being exploited by health system (such as when ill patients are being transported by volunteers).

In a related study of nonprofit organizations within rural health counties in the United States, it was determined that nonprofit organizations did work collaboratively with other organizations in the regions, albeit they were more likely to collaborate with other nonprofits than with state-funded organizations (Snavely and Tracy 2000). The most common type of collaboration had to do with case management; that is, it was quite

common to share information about services and clients, and to refer back and forth among organizations. There was also a high level of collaboration with respect to community-level needs assessment and planning, but when it came to service integration, certain types of activities were more common than others. It was common to share space, and perhaps volunteers, and to join forces to write grants. However, it was less common to actually share common guidelines or standards for service; those activities which seemed to represent 'core' activities for nonprofit organizations were less likely to be planned and delivered jointly or under some collaborative agreement. The level of interorganizational planning (with respect to activities that would directly impact the organizations, as opposed to reflecting some community level dimension) was also less common.

There is probably no a priori reason to look only at research done within rural areas to inform VHS/FHS. Research done elsewhere can also probably inform relationships held in rural areas. However, as in many situations, the context within relationships and interactions is somewhat specific (often large geographical areas; tendency in many countries to move at least secondary level health services to larger centres) and presents a unique set of challenges. This is somewhat balanced by a context where individuals know one another and there is historically a tradition of 'helping one's neighbours.'

Summary

There is very little published literature which specifically addresses the issue of interactions and relationships between organizations in the VHS and FHS. Those which are most relevant are annotated in Appendix 5. No doubt, however, there is much research done relating to collaborations or partnerships at the community level in which the focal collaborations involve one or more voluntary agencies, such as in the examination of mental health networks by Provan (1998) or such as happened in Canada in the Heart Health Initiative (Stachenko 1996; Elliot et al 2000). However, there is no explicit attention paid in published research to the specific role, contribution and actions of voluntary organizations, as compared to others. It is not clear that this differentiation is necessary either, but this conclusion should not be assumed in the absence of evidence. Some have reflected on the macro level relationships between governments and voluntary agencies when they describe the respective role of the voluntary sector as being complementary, supplementary or adversarial. Four general roles were identified which the voluntary sector played in achieving their goals. These are direct service provision, playing a mediating or linking role, support of citizen involvement and the democratization of health information. The third of these (support of citizen involvement) is concerned with playing a larger role in society than necessarily helping to improve the health system, as it concerns the enabling of citizens to contribute to society (regardless of the substantive issue of the voluntary organization). The linking and mediating role is a large one for the voluntary sector, as organizations are often comprised of representatives of groups in society with a particular interest, and therefore they provide a focal point through which other organizations can interact for purposes of collaboration on shared issues, or for seeking input from a particular constituency.

With respect to specific actions and interactions taken by organizations in the VHS, there was a range identified in the literature. These included direct service provision (sometimes through contracting), referrals among organizations (voluntary organizations both accepting referrals and also making referrals), and collaboration with other organizations. A small number of studies were identified with particular reference to interactions with primary health care services or as relevant to a rural setting. While there are not enough studies to make any definitive statements about the role of the voluntary sector in either primary care or rural health care, they do begin to provide some information about these two particular foci.

CANADIAN VIGNETTES

Because literature which is specifically Canadian is rather sparse, and because it is often helpful to test conceptual ideas against the 'real world', several vignettes describing a range of Canadian activities is included below. These vignettes are used for illustration purposes. They vary in the nature of the interaction between the voluntary health organization (VHO) and other elements of the health system. In the Hepatitis vignette, the VHO advocated to government to adopt an immunization scheme that would cover students who had been missed in an earlier period. The VHO then went on to be involved in program delivery. In the Cultural Health Brokers vignette, the fluid and flexible nature of VHO is exemplified, as the VHO underwent several mandate shifts and organizational forms in a relatively short period of time. The Newfoundland Heart Health vignette illustrates a community-level action which was sponsored and instigated initially by a government department and which gave rise to a relatively autonomous community-level activity that felt only very weak links to the sponsoring government program.

Vignette A. Hepatitis B Vaccinations in Calgary

In October 2001, high schools sent home a letter from the Deputy Medical Officer of Health for the Calgary Health Region (CHR), indicating that the Region, in partnership with the provincial department of health, and the Canadian Liver Foundation (CLF), was offering Hepatitis B vaccine at the school to all Grade 12 students. Students are now vaccinated against Hepatitis B in Grade 5, but this has only been the case for the past six years. The Canadian Liver Foundation realized that there were older students who had not had the vaccinations that were now routine. They made a presentation to the Social Policy Committee of government and convinced the Minister of Health that implementing a program to vaccinate the older students was a good idea. The last of the unvaccinated cohorts is in Grade 12 this year, and the Canadian Liver Foundation in Alberta initiated a 'Hepatitis B Catch Up' program three years ago. The program is a joint effort between the provincial department, the regional health authorities in the province and the Canadian Liver Foundation. The vaccine was bought through a tendering process by Alberta Health and Wellness, and was distributed to the health regions for administration to Grade 12 students. Promotion of the program has been done

primarily by the Canadian Liver Foundation with funding from Alberta Health and Wellness, a portion of which had come from the pharmaceutical company supplying the vaccine. Promotion of the program is very important, as it requires students to have three rounds of vaccinations over a six-month period. (Karen Grimsrud, personal communication 2001; Maria McNair, personal communication 2001)

Vignette B. Heart Health in Clarenville, Newfoundland

A group of volunteers in the community of Clarenville in eastern Newfoundland mounted and ran a community-based heart health program for several years in the 1990s. They initially received a small amount of funding ($8000) from the Canadian Heart Health Initiative which was providing funds under a national applied research initiative. The inaugural volunteer chair of the Clarenville Heart Health Program is very proud of what they were able to accomplish, totally with volunteer efforts. At the end of the funding period, there was money to give back to the province. The local committee was not formally constituted, but was spawned, and 'sponsored' to a modest degree, by an umbrella initiative of the federal Department of Health. However, the committee operated very independently and made its own decisions about what activities to undertake in Clarenville. When the original chairperson of the Initiative left to pursue other interests, the initiative gradually disbanded and at the current time, activity is minimal (Weinheber, personal communication 2001).

Vignette C. Brokering Health Information for Different Cultures in Edmonton

1993 a training program in multicultural childbirth education was initiated in Edmonton by a consortium which included the local board of health, three large urban hospitals, a community college and nine immigrant women from six ethnic communities. The origin of this initiative was the board of health's interest in rendering their prenatal education programs more accessible for immigrant and refugee families. Research had found common struggles with language barriers, lack of familiarity with the health care system and "conflict" between traditional health beliefs/practices and western medicine. The research results suggested the strategy of training and involving health educators from immigrant/refugee communities. Pilot training was launched as a collaboration between the members of the coalition. It involved a set of core skills in health promotion that enabled them to provide support to minority women and also to assist public health nurses to increase their knowledge of cultural issues. In 1995, a three-year grant from Health Canada enabled the formal recruitment of the Multicultural Community Health Developers (MCHDs). During this period of activity the scope of practice of the MCHDs evolved to 'cultural brokering' and included a broader range of community development activities related to health. In 1998, the Multicultural Health Brokers Cooperative was organized with a mandate of supporting immigrants and refugee individuals and families in attaining optimum health through health education, community development and advocacy support. The Cooperative is a self-governing body whose members work both

within projects sponsored by the Coop and also from a base within social service and health institutions serving about seven cultural communities. As a workers' cooperative, the Multicultural Health Brokers are guided by the three fundamental principles of cooperatives: direct responsiveness and accountability in relation to immigrant/refugee families and communities, democratic governance with members of the cooperative sharing decision-making power and grounding in social objectives of equity and justice. At present (2002), the MCHB Cooperative has major contracts with two health institutions. Within the contractual relationship is a commitment to support incremental changes towards greater cultural responsiveness to the needs of immigrant/refugee populations. Given the holistic nature of the health brokering practice, much of the MCHB's work involves liaising between immigrant/refugee families and other key sectors (children services, education/employment, recreation, preventive social services, income security and housing). Such work, which constitutes 50 percent of the time commitment, is not yet recognized by such sectors in a formal manner. The MCHBs carry on such work on a voluntary basis, while seeking to support these sectors in recognizing the issue of inequitable access, as well as the need for responsiveness towards the unique circumstances of immigrant/refugees. The MCHB Cooperative continues to survive with accessing one-time or pilot "project" funding (from federal/provincial governments and foundation) to pursue work in addressing the emerging health and social health issues within immigrant/refugee communities. The MCHB Cooperative's relationship with public institutions is such that while it is of a contractual nature relating to services, there is explicit autonomy in relation to advocacy and efforts to influence policy development (Maria Mayan, personal communication; Yvonne Chiu, personal communication; Martinez-Ortez (Unpublished)).

REFLECTING ON THE LITERATURE AND CANADIAN DATA (ANNUAL REPORTS AND VIGNETTES)

The literature and annual reports provide two different windows into the area of interactions between organizations in the VHS and the FHS. This has not been a predominant focus of research to this date, so the body of knowledge is not well developed. Examination of Canadian annual reports was instructive, despite the obvious limitations of looking at national level annual reports. There was considerable overlap in the types of interactions described. In the Canadian annual reports, actions specifically referring to direct interaction with the FHS included direct funding, collaboration, contracting to provide services, support of third party intervention, and arm's-length attempts to influence the other organization (such as through advocacy). While the literature reviewed was not specifically focused on interactions between VHOs and the FHS, the following actions were identified: mediating or linking; direct service provision, making health information much more accessible, and supporting civic involvement. There is clearly some overlap between actions identified from the two sources. Collaboration is a form of linking and mediating, although there may be mediating and linking functions done by voluntary organizations that are not necessarily collaborative in nature. The indication from annual reports that VHO provide direct funding to health delivery organizations (often for purposes of staff support) is somewhat surprising, given

the differing level of resources available to the respective organizations. An explicit examination of the types of interactions between the two sectors with a view to trying to understand the intended and realized impacts would be instructive.

TOWARDS A CONCEPTUAL OVERVIEW OF THE RELATIONSHIP BETWEEN THE VOLUNTARY HEALTH SECTOR AND THE FORMAL HEALTH SYSTEM

Conceptual frameworks serve a useful purpose in shaping and interpreting research in a particular field. Clearly articulated conceptual frameworks enable the interpretation of existing research which may be available, but which needs to be interpreted within a certain frame. Even if the context within which one is interested in interpreting the research is not identical to the one presented in the research, if one has a 'frame' through which to view the research it may be more fruitful (Robinson 2001). In addition, a conceptual framework can help to create a path to guide sequential research projects so that they make an incremental contribution to the knowledge domain.

It is too early to propose a theory of organizational interactions involving the voluntary sector. However, it is useful to identify some dimensions that it may be necessary to consider in an overall consideration of organizational relationships in the voluntary sector. A discussion of some of these dimensions follows. The identification of these dimensions was done in a workshop involving several researchers and practitioners during which the results of analysis of annual report contents and literature were considered. This consideration, combined with extensive personal knowledge and experience, resulted in the identification of several dimensions which need to be considered in the development of a comprehensive conceptual framework through which to examine interactions between the VHS and the FHS. Participants in this workshop are listed in Appendix 3.

Dimensions that need to be examined or at the very least clarified in ongoing research include those listed below. It is important to consider them so that as research is done with a view to helping us understand organizational relationships and influence mechanisms, it is clear which part of the conceptual puzzle is being highlighted by any individual study.

Extent of formal organization of volunteer efforts. Earlier in this report, there has been reference to this dimension, and it was indicated that the present work was interested in the role and influence of formally constituted organizations and their interactions with other organizations in the health system. Therefore, the focus is explicitly organizational, in contrast to much work that is done which collects information about the role and contributions of individuals to society. So, this dimension is a defining one with respect to the current work, but there are other dimensions which need to be specified in any particular body of work, so that it is clear how that research is contributing to understanding of the organizational impact of the voluntary sector on the health system.

Power relations between and among organizations involved in interactions. When trying to understand the nature of interaction between organizations and the impact of those interactions, the relative power of the two organizations must be taken into account. This might include dimensions such as the size of the organizations, resources available (financial and human), the decision-making authority of the representatives involved, the level of autonomy of the organizational entities, and the level of prestige accorded the organization by society at large.

Clear articulation of the differentiation between public, private and voluntary sectors. It is intuitively appealing to split the world into three separate and distinct components, but this is not easily possible in a way that helps to guide research. The focus in the current work has been on interaction between organizations in the voluntary sector, and those in the FHS (including both government and health service delivery organizations). There are organizations in the health system that are private as well as publicly funded. Physicians in private practice (either singly or in groups) are perhaps the most obvious ones. Even in this case, there could be debate about whether these are classic private sector organizations as most revenue accruing to physicians comes from public sources. Are physician practices best viewed as private sector organizations or as publicly funded services managed through a third party funded by government? In any case, there are private organizations involved in delivering health-related services as well, so it may not be adequate to focus attention only on the voluntary sector and publicly funded organizations. In a complete view of the health system, organizations within the private sector also play a role, whether that is in providing goods or services (massage therapy clinics, health food products, counseling services). Increasingly as well, the distinctions between the sectors are blurring, as charitable organizations adopt strategies more commonly associated with private sector businesses, and businesses are increasingly concerned with more socially-oriented dimensions such as worker health and other dimensions important to society at large (e.g. environmental issues). At the very least, it is important to specify what the assumptions are when labeling organizations coming from one sector or another.

The nature of the organization. Certain key characteristics of an organization make that organization more or less able to engage and be effective at different types of activities. These characteristics include such things as the organizational structure, number and type of staff (paid, unpaid; level and types of expertise), and governance (member organization, corporate structure, cooperative). The origins of the organization may also be important. Many voluntary organizations are created as a result of an identified need by stakeholders (hospitals, physicians groups) within the health system; others truly arise from community-based concerns and are 'grassroots' in origin.

The focus of intended impact. The health system is complex, and there are varying levels and locations of intended impact. The level varies from local community to provincial and national; and the focus of attention might be health related activities in the local community, or in primary, secondary or tertiary services, or at the policy or societal levels.

Underlying assumptions and values. This dimension can include a wide range of values, attitudes and assumptions affecting the interactions that take place between the sectors, and are often unspoken. It may include such things as mistrust or dislike of the organization in the other sector, or a general mistrust of all organizations who represent the 'system' or who represent 'do-gooder' volunteer organizations; or an underlying belief that voluntary health organizations should 'act like businesses,' for example.

Health dimensions of interest and their definitions. The dimension and definitions of health-related concepts that are of concern impact the scope of interactions of interest. For example the concern could be with physical aspects, mental, social or spiritual aspects, or indeed may be related to underlying determinants of health (which would allow conceptually a much broader range of activities to be included within a health discussion).

Task or problem attributes. The specific nature of the issue which is being addressed in the course of interactions between the VHS and FHS needs to be considered in trying to understand the mechanisms of influence. For example, interorganizational interactions between VHOs interested in reducing the impact of tobacco use on the health of Canadians are multidirectional, longitudinal and it seems, never ending. On the other hand, if the issue at hand is to ensure public coverage of some medical device which makes the life of an affected person much easier, then the nature of interaction is very focused, and there is a clear end point. These two situations would lead to much different interaction between VHOs and the FHS.

The context for the interaction. This is a huge category of dimensions that no doubt will eventually need to be subdivided. Characteristics of the context or situation which may theoretically impact the nature of interorganizational interactions include (but are not limited to): the prevailing government philosophy about voluntarism and contracting out; the characteristics of health reform in a region; the geographic setting (urban, rural); the ethnocultural community of interest; the population profile (number and nature) of voluntary organizations within a particular region; public opinions with respect to the VHS and the FHS; or, the degree and nature of community need.

Outputs and Outcomes. There has been precious little explicit attention paid in the literature to date on what the 'hoped for' outcomes are with respect to interactions between VHOs and the FHS. One can imagine that they include such things as ultimately changing the nature of services provided by the public system (which may be why a small VHO would provide direct funding for staff to a health delivery organization with much larger resources), or changing public policy, or improving health outcomes in a specific subset of patients. We know this to be the case when program evaluations are done which focus only on the activities of a VHO. What isn't known is the intended outcomes of interactions between the sectors. It is not unreasonable to think the outcomes are similar, but the means of achieving them are different, perhaps depending on context.

SO WHAT?

Given that there is so little emphasis on the organizational relationships between the voluntary sector and the FHS in the literature and in publications arising from the sector itself, one must ask "Why is this important to consider?" There are several reasons why it may be helpful to understand more about the interactions and relationships between organizations in the VHS and in the FHS. We live in an organizational world, and it seems imperative to understand the impact of organizations within the health care system. Because of their unique nature (often fairly informal but flexible in mandate and approach) and because they are funded directly (as in the case of publicly donated funds) or indirectly from public funds (as in the case of government grants or contracts), it is more difficult to gain an appreciation of the role and contributions of VHOs. However, because we are increasingly acknowledging the importance of the voluntary sector, it behooves us to increase our understanding. Some policy questions which could potentially be at least partially answered by having improved knowledge of organizational actions and impacts of VHOs include:

1. What may be the potential impact of government grants to VHOs?
2. What contributions do VHS organizations make to health in Canada?
3. What models of interaction translate to improved health or improvements in health services delivery?
4. Can voluntaries 'pick up the slack' (for example, in transition from institutional care for mentally ill, to the community)? Under what conditions can they pick up the slack?
5. In which situations is contracting with a VHO to provide services advantageous?
6. In what situations can a VHO play the most effective role in linking or mediating between various components of the health care system?

The present work is one piece of a mosaic that may eventually lay the foundation for work which directly informs the policy questions identified above.

RECOMMENDATIONS FOR FURTHER RESEARCH

1. Observational and descriptive studies which describe the nature and extent of organizational interactions between the VHS and the FHS and the impact of those interactions. This may include, but not be limited to interactions which are collaborative in nature. Ideally these would be done within a clearly defined context such as specific size of community, within a specific health focus or defined according to one or more of the dimensions that are identified in the earlier discussion related to a conceptual framework. Both quantitative and qualitative studies are needed.

2. A systematic review of factors contributing to successful interoganizational relationships involving organizations in the voluntary sector (including unpublished literature). Most of the literature does not focus on the type of

organizations that are collaborating. Much of the research may be relevant to voluntary organizations, but it is not clear to what degree that is the case, or if in fact there is any particular reason to view voluntary organizations differently with respect to collaboration processes. Given the huge range of voluntary organizations in size, intent, governance, etc. it is not clear the degree of relevance to voluntary sector.

3. Population level studies which focus on things such as

    a. Comparison of the relative nature and extent of contributions by volunteers engaged within the FHS (such as in hospitals and those organizations which are formally constituted within the voluntary sector). The focus in this paper has been on organizational influence and interaction. This is in contrast to much of the research which has focused on volunteering, with individuals as the point of departure. There are many dimensions upon which knowledge gleaned about the activities and impact of volunteers in any particular health care setting make no difference if the volunteers are working within the umbrella of a public organization or within a voluntary organization. However, the focus of interest here is on organizational interaction and influence. As there is very little work done in this area, teasing out these interrelationships will require careful thought.

    b. Research to describe from the system level, the profile (number and nature) of voluntary organizations present in a particular defined community. The impact and role of a VHO in an organizational field that has one VHO focusing on a particular health issue may be quite different than within a field that contains 10 VHOs focusing on one health issue.

4. Examination of the impact of voluntary organizations in different contexts in order to identify the confluence of dimensions in which voluntary organizations have a unique comparative advantage for effective action.

CLOSING COMMENTS

The development of a body of knowledge relating to the role and impact of voluntary health organizations on the health of Canadians is in the early stages. While there are individual studies which inform various aspects of the actions of VHOs, there is insufficient work to enable a general understanding. In the short run, it is important to outline a conceptual framework within which to view these relationships so that research contributes to our understanding in an incremental way. This paper has made beginning steps in that regard. While this body of knowledge develops, it is helpful to view the field through several different lenses: organizational theory, political science, economics, geography, sociology. Increasing our understanding of organizational impact will provide some return on investment to both voluntary health organizations who are trying

to make a difference, and also to funders, including the government, who make decisions about resource allocation on a regular basis.

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APPENDIX 1: EXCERPTS FROM ANNUAL REPORTS SUGGESTING DIRECT INTERACTION WITH THE FORMAL HEALTH SYSTEM

Direct Funding

1. Work began on a system to develop a more formal relationship between the MS Society and the MS clinics. It is anticipated that affiliation agreements and a funding formula for clinics will be developed in the future

2. The Foundation has once again provided partial salary support for 18 registered nurses attached to selected neurologists or VON clinics across Canada as part of its Clinical Assistance and Outreach program. In addition, teams of neurologists and nurses have visited distant communities far and wide to provide support and assistance to those who do not have easy access to the major Movement Disorder Centres.

3. The Foundation provides supplementary funding to CF clinics and transplant centres through its Clinic and Transplant Centre Incentive grant programs. The funds promote additional support that would not otherwise be available to members of the multidisciplinary team – funds to attend medical conferences, to build professional knowledge of CF, and strengthen the CF network. Ensuring that clinical personnel continue to learn about CF care, contribute to world knowledge, and remain well-informed about DF treatments, leads to consistent, superior care across the country.

Contracting by Voluntary Organization

4. In September, 1999, CMHA was designated as the Mental Health Affiliate partner for the Canadian Health Network, a national, bilingual, Internet-based health information service funded by and in partnership with Health Canada. ....

5. The Canadian Cancer Society is the cancer affiliate for the Canadian Health Network (CHN), a growing network of over 600 Canadian, nonprofit organizations. Funded by Health Canada, this network provides a national, Internet-based, health information service.

Organizational Representation

6. Society staff worked on government task forces and voluntary agencies to address common concerns and recognize the importance of the voluntary sector. (Alzhemier Society)

Collaboration

7. We sought fruitful partnerships and engaged in the formation of the Neuromuscular Research Partnership (NRP), a joint initiative between the MDAC, the ALS Society of Canada and the Canadian Institutes of Health Research. This partnership allowed us to pool resources for the administration of combined research activities, while providing the critical mass required generating increasing financial resources for research.

8. The Canadian Cancer Society and its research partner, the National Cancer Institute of Canada are very proud of the role they have played in partnering with Health Canada and the

Canadian Association of Provincial Cancer Agencies to help develop the Canadian Strategy for Cancer Control. Dorothy (Dorothy Lamont, former Chief Executive Officer) developed a relationship with the federal government that has given cancer control the ear of the government. A consortium of Health Canada, the Canadian Association of Provincial Cancer Agencies, the CCS and NCIC – brought together by Dorothy – is fine-tuning the first Canadian Strategy for Cancer Control.

9. In partnership with other members of the Canadian Alliance on Mental Illness and Mental Health, CMHA continues to raise issues of concern at the Federal level that have an impact on communities throughout Canada.

10. Lupus Canada also continues to support the tripartite partnership with Retrocom and CIHR to fund a post-doctorate fellowship to enable new specialists to focus on lupus.

11. The Canadian Diabetes Association believes that reaching out to local communities is vital. For example, we partnered with a Dartmouth hospital on a community health session about diabetes. ... In Kingston, Ontario our partnership with a grocery chain and local dietician to offer healthy cooking classes helped many people with diabetes leran more about meal planning.

12. Nationwide, the Canadian Diabetes Association is active in alliances for health promotion – working cooperatively with other health related associations. This includes the Alliance for the Prevention of Chronic Disease in Manitoba, the Diabetes Complication Prevention Cooperative in Ontario and the Health Charities Network of Nova Scotia.

13. The Canadian Diabetes Association has played an active leadership role in the development of the federal government's Canadian Diabetes Strategy.

14. Canadian Diabetes Association divisions have also seen progress as they continue to work with provincial and territorial governments on their diabetes strategies.

15. We (Alzheimer Society) partnered with Astra Zeneca Canada Inc., Astra Zeneca US and the Canadian Institutes of Health Research to fund up to four grants into the causes, diagnosis and treatment of Alzheimer Disease.

Support of Third Party Activity

16. In 2000, the CCFF's site visit program sponsored reviews of five clinics to help ensure standardized, high quality clinical care across Canada. Site visits conducted by members of the Clinical subcommittee and other Canadian clinical leaders allow the clinic team and reviewers opportunities to discuss national standards of care: to promote and exchange ideas on medical, administrative and social issues, and to offer third-party support.

17. The common goal was to promote meaningful employment opportunities for consumers across different geographic regions. This funding has enabled local sites to build on their existing employment programming capacity by exploring innovative job creation strategies, strengthening community partnerships and expanding employer educational initiatives.

Arm's-Length Influence

18. ...our president presented a brief to the Senate Sub-Committee to update 'Of Life and Death' chaired by the Honorable Sharon Carstairs. ... We are also working with other national stakeholder groups to convene a planning meeting for a national strategy for end-of-life care (Canadian Palliative Care Association Annual Report 1999-2000).

19. In addition to advocating for the rights of people with diabetes, we have increasingly dedicated resources to government relations and public policy to ensure that the disease is a national priority. We actively advocated for a diabetes institute named by the federal government's Canadian Institutes of Health research. (Canadian Diabetes Association)

APPENDIX 2: EXCERPTS FROM ANNUAL REPORTS SUGGESTING INDIRECT INTERACTION WITH THE FORMAL HEALTH SYSTEM

CMHA continues to collaborate with our partners in CAMIMH (Canadian Association for Mental Illness and Mental Health) to press for a national action plan on mental illness and mental health. Together with our partners, the Canadian Psychiatric Association, the Mood Disorders Society of Canada, The National Network for Mental Health and the Schizophrenia Society of Canada, we have developed a model for citizen engagement and met with numerous political decision makers at the national level to raise the profile of mental health and illness issues on the federal policy agenda (Canadian Mental Health Association. Annual Report 2001).

The Primary Prevention of Neural Tube Defects and Preconception Health: Integrating the Message Meeting was an attempt to get health professionals together to discuss the status of awareness of the role of folic acid in prevention of NTD's (Spina Bifida and Hydrocephalus Association of Canada Annual Report for Year Ended April 30, 2000).

..the Asthma Society of Canada will focus on... the development of a network of professionals across Canada to assist in the delivery of our programs in local communities (The Asthma Society of Canada Annual Report 2000).

We hired additional professional staff to provide better service (The Asthma Society of Canada Annual Report 2000).

The CCS is working with the Canadian Dermatology Association to maximize effectiveness of Sun Awareness Week in May, and to promote skin cancer issues and awareness through the year (Canadian Cancer Society Annual Report 1999-2000).

Resource Centre Directors and Support Workers from across Canada accomplished the following:

- 8,161 contacts with individuals with HD and their families
- 5,300 contacts with health professionals
- 127 in-services for hospital staff, nursing homes and related health care facilities

(Huntington Society of Canada Commemorative Millennium Report 1999-2000)

Our partnerships with Canadian health care professionals through our Clinical and Scientific Section and Diabetes Educator Section is strong. More than 1500 participants attended the Section's third annual conference in Ottawa.... (Canadian Diabetes Association 2001).

APPENDIX 3: LITERATURE SEARCH STRATEGIES

The major goal of this literature search was to identify articles that include a description or analysis of relationships between organizations in the voluntary health sector and the formal health system (FHS).

The literature search included a search on book chapters and eight databases: Academic Search Premier, Business Index ASAP, CINAHL, HealthSTAR, Medline, ProQuest, Sociological Abstracts, and Social Work Abstracts Plus. The majority search covered books and published articles between 1992 and 2001 and a small proportion of the search was beyond 1992. The search strategies incorporated a keyword search of databases and a scan search on the table of contents of eight journals. The keyword search started with single keywords. If certain keywords yielded a large number of articles, the search would then combine with other keywords. For example, a keyword search on "health care delivery/health care" yielded 50415 articles. When this combined with "voluntary health agencies/voluntary organizations," there were 46 articles found.

The keywords being used could be divided into six subcategories:

1. Voluntary/voluntarism/volunteers/non-paid staff or workers
2. Voluntary/nonprofit health care
3. Voluntary/community agencies/associations/organizations/sector
4. Health care/primary health care/rural health care
5. Health service delivery/health care services
6. Collaboration/partnership/coordination/coalition/task force in health care

The tables of contents of the following journals were scanned:

1. Nonprofit and Voluntary Sector Quarterly
2. Nonprofit Management and Leadership
3. Academy of Management Review
4. Nonprofit world
5. Human Organization
6. British Medical Journal
   http://www.bmj.com/bmj/index.html
7. Canadian Medical Association Journal Online
   http://www.cma.ca/publications/index.html
8. Social Science Research
   http://www.idealibrary.com

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APPENDIX 5: ANNOTATED BIBLIOGRAPHY

(* denotes Canadian focus)

Addington-Hall, JM; MacDonald, LD; Anderson, HR; Chamberlain, J; Freeling, P; Bland, JM (1992). Randomized controlled trial of effects of coordinating care for terminally ill cancer patients. BMJ 305: 1317-1322.

The objective of this study was to measure the effects on terminally ill cancer patients and their families of coordinating the services available within the NHS and from local authorities and the voluntary sector. The study took place within an inner city district in London, England. All patients received routinely available services. Coordination group patients received the assistance of two nurse coordinators who attempted to ensure that patients received appropriate and well-coordinated services, tailored to their individual needs and circumstances. Univariate analysis of many single measures was done, and although there was a benefit to being in the intervention group for several indicators (less vomiting, less itchy skin, more likely to call specialist nurse during night, carers feeling less angry after death), on balance the conclusion was that the findings did not support a positive outcome from the intervention. The authors attributed this, at least partially, to the fact that there were nurse specialists in the coordination role, and they may have been less effective in the role than a non-specialist, as the nurses could provide some expert help themselves, so that the motivation to refer to other services was perhaps less. Another explanation was that there was no additional resources to supplement services when need indicated, so therefore coordination and referral to services which did not exist, was a limiting factor.

Billis, David and Glennerster, Howard (1998). Human Services and the Voluntary Sector: Towards a Theory of Comparative Advantage. *Journal of Social Policy*: 27 (1):79-98.

This article explores whether human service organizations in the voluntary sector possess characteristics which might reflect a comparative advantage over the for-profit and public sectors with respect to certain sorts of users. The authors criticize most attempts using economic theories to 'explain' the voluntary sector as attending only to the supply side of the equation. This line of thinking involves consideration of the different drivers in the various sectors (voters, profit, multiple stakeholders in the voluntary sector), organizational structures, revenue sources and types of workers. It is argued that the demand side of the equation is also important. It is proposed that certain combinations of disadvantages (financial, personal, societal, community) in groups within society provide a milieu in which organizational characteristics of voluntary agencies provide a comparative advantage in addressing the needs of these disadvantaged groups. The very complexity and ambiguity (e.g. lack of clear role differentiation among staff and volunteers, board members and service deliverers) that often characterizes voluntary agencies provides a unique opportunity to address issues within disadvantaged communities. This is because, the authors argue, ambiguity implies a flexible, changing and informal structure. Logical extension of this argument would cause one to question

the viability of voluntary agencies that attempt to respond to large-scale needs outside the core areas of personal, societal or community disadvantage, and also call for careful thought on the part of voluntary agencies, when contemplating the world of contracting with governments through which to provide services.

***Birdsell, J.M.; Schwann, M.E. & Tremblay, R. (1992). Reaching native groups in the Northwest Territories: a report of a joint project between government and a voluntary agency. *Can J Pub Health*, 83(5):335-6.**

This is a description of a case where a health charity (Canadian Cancer Society) worked in collaboration with the Departments of Health and Education in the northern Canada to address shared goals related to health education and cancer prevention. The Cancer Society felt it was important to work with existing systems which could deliver public education in a challenging geographic and cultural setting, and to help residents meet needs which they themselves had identified. This was felt to be important to establishing a working relationship upon which future specific cancer prevention programs could be developed. The Department of Health had developed a program to teach lay community health workers (CHW) to work in their communities. The manual was intended to assist interpreters in promoting healthy lifestyles. After discussion between the CCS and government departments, a decision was made that the CCS would produce large diagrams of different parts of the body. It was felt a good basic knowledge of the body would contribute to a program designed to teach about cancer. The diagrams, which were produced in large size and laminated, were unlabelled, so that CHW could label them in one of the twelve languages or dialects used in the region as appropriate. They were distributed to 160 organizations (community health workers, nursing stations, school principals). A follow-up survey of recipients six months after distribution showed that 82 percent of respondents had used them in some way, with schools having the highest use, and CHRs the lowest rate.

Black, Bruce L. & Ades, Terri B. (1994). American Cancer Society Urban Demonstration Projects: Models for Successful Intervention. *Seminars in Oncology Nursing*, 10(2): 96-103.

Three projects designed to demonstrate how to implement cancer prevention and control programs that ensure high-quality, accessible and affordable screening and early detection services for underserved populations are described. Each of the projects was implemented in collaboration with other agencies in the particular location, and no single model emerged, although each included activities designed to overcome individual barriers and structural barriers to accessing services. The three approaches taken in the projects included a mass screening model, a primary health care model and a patient navigator model. The authors concluded that location of cancer control activities in primary health car settings located in the community (as opposed to hospital setting) increased service availability, accessibility and utilization. Successful educational outreach strategies identified through these projects included: hiring outreach staff who are indigenous to the community, piggybacking onto other community program agendas, avoiding 'cancer only' approaches, culturally relevant and community specific materials,

simple educational messages, emphasizing the person's ability to affect their own health, and emphasizing wellness and health (not cancer). It is not clear what the extent of the ACS's role was. These projects were apparently sponsored by the voluntary agency, but the projects were described in their totality with respect to the activities included, so it is not possible to describe precisely the role and impact of the ACS in these projects, but it seems clear they were instrumental in the establishment of the projects, at the very least.

Coston, Jennifer M (1998) A model and typology of government-NGO relationships. *Nonprofit and Voluntary Sector Quarterly*, 27(3): 358-382.

This article develops a model and typology of government and non-governmental relationships. Building on the literature in the area, the model defines eight possible relationship types based on several dimensions: government's position toward institutional pluralism, the relative balance of power, the degree of formality. The eight types (from that which reflects the most 'distance' between government and NGO's to that which reflects two organizations able to philosophically 'link' to accomplish shared goals) include repression, rivalry, competition, contracting, third party government, cooperation, complementarity, and collaboration. On the one extreme a repressive relationship is characterized by government resistance to institutional pluralism, no NGO linkage with government, asymmetrical power relationship (government advantage), and unfavourable government policy (perhaps even outlawing NGO's). Collaboration, on the other end of the spectrum, is characterized by government acceptance of institutional pluralism, high linkage with government, symmetrical power relationship, favorable government policy, information and resource sharing, joint action and mutual benefit. Repression is probably not observed in Canada, but may be common in certain areas of the world under repressive regimes. The authors assert that the model and typology are designed to assist government, NGOs, donors and practitioners to identify and promote the most productive government-NGO relationship for a particular context. It is suggested that this model can be helpful at both the general and specific levels, and be examining the particular dimensions inherent in a specific type of relationship, that actors can identify intervention points in a specific relationship. The model may be useful at the problem framing and direction-setting stages of interorganizational activities.

***Elliott, Susan J.; Jolin, Mari Alice & Walker, Rosemary (2000). Partnering in and for Heart Health Promotion: Findings from a survey of community organizations. *Canadian Journal of Public Health*, May-June: 229-233.**

This paper reports on the results of a survey of 283 community agencies with respect to their level of involvement in heart health promotion activities. These agencies have no formal linkage to the public health system through budgets, staffing or mandate. Included in the sampling frame were four voluntary organizations (Heart and Stroke Foundation, Canadian Cancer Society, Lung Association, YM/YWCA), boards of education, and municipal Parks and Recreation departments. Levels of involvement in each of the four activities (tobacco use, physical activity, nutrition, general heart health) differed significantly by organization type, depending on the distinct mandate of the group in question. The average number of partners was highest for the tobacco use topic

and the health unit was the most frequently mentioned partner for all areas. Collaboration (as opposed to cooperation or coordination) was mentioned as the most frequent type of working relationship. Collaboration was defined as including shared ownership of activities, and organizations planned and implemented activities jointly. The percent of organizations reporting collaborative activities was highest in the tobacco use area. It is clear that, within Ontario and the Heart Health area, voluntary agencies participate actively in community collaborations to influence risk factors associated with heart disease.

Grant, Clare; Goodenough, Trudy; Harvey, Ian & Hine, Chris (2000). A randomized controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector. *BMJ* 12 February:419-423.

One hundred and sixty one patients with psychosocial problems visiting general practitioners in Britain were randomly assigned to standard care or to a project which employed a facilitator to make an assessment and refer patients to appropriate local and national voluntary organizations. The patients referred to the Amalthea project experienced better outcomes on most dimensions measured using validated tests (psychological wellbeing, quality of life). The one dimension where no difference was detected was perceived social support. Costs associated with the two arms were assessed (with the exception of costs incurred by the voluntary agencies). The authors conclude that referral to the project and subsequent contacts with the voluntary sector resulted in clinically important benefits compared with usual general practitioner care in managing psychosocial problems, but at a higher cost. The increased costs in the treatment arm were due to primarily to the cost of the referral facilitator, as costs associated with primary healthcare (team contacts, prescribing and referrals) were actually higher in the standard treatment arm. It is difficult to determine the contribution of the voluntary sector agencies to the improved health outcomes, as the number of referrals was similar in both arms of the study.

Kapur, Kanika & Weisbrod, Burton A (2000). The roles of government and nonprofit suppliers in mixed industries. *Public Finance Review*. 28(4): 275-308.

This research examines organization level behaviour of agencies providing similar services (homes for the mentally handicapped and nursing homes) within both the government and nonprofit sectors. The authors suggest that as both these types of organizations are constrained by the fact that they cannot generate profits for shareholders or directors, they should act similarly unless other factors are influencing their behaviour. They used consumer access (as measured by waiting lists) and output quality (measured by patient satisfaction) as indicators of behaviour of the respective organizations. They used data from national surveys done in the US in 1976 and 1987. They find that they did not behave similarly. Government agencies were less likely to have waiting lists, which the authors interpreted as a willingness by government agencies to sacrifice quality in order to accommodate more clients. With respect to customer satisfaction, six measures were used. In two of them (overall satisfaction and satisfaction with buildings and grounds) there were no statistically significant differences. However

on the other four measures (rooms and furnishings, staff, social activities), the level of satisfaction was higher for nonprofit institutions than for government facilities in both the nursing home and mentally handicapped facilities. This is interpreted as reflecting the position that governments are suppliers of last resort, and will not turn anyone away, whereas nonprofits, as they are not philosophically or legally obligated to serve all, can limit access to improve quality. This is an American study, so its relevance to the Canadian system needs to be examined closely. The study does also not provide information which might allow an assessment of whether there are institutional factors which may predispose different client groups within each of the sectors. Nevertheless, the methodology and underlying hypothesis are worthy of consideration.

Kramer, Ralph M (1994). Voluntary Agencies and the Contract Culture: "Dream or Nightmare?" *Social Service Review*. March:33-60.

The emergence of purchase of service contracting (POSC) as the primary method of delivering personal social services in the US led to this analysis of related research. Three basic models have been used in the study of POSC: partnership, market, and interactional process. Although few studies come from a particular theoretical base, those that do tend to be guided by resource dependence or political economy models, and to a lesser degree an institutional perspective. In an overview of the research to date, the authors identify four different rationales for POSC (legislated mandate, ideology, rational decision making and pragmatic expedience) and feel that legislative and pragmatic administrative and fiscal restraints are more predominant. Consequences of POSC for the service delivery system, the nonprofit organization and also the government are discussed. Relatively little is known about the effects of POSC on the service delivery system or the governmental agency. Some research identifies impacts on the nonprofit organization (e.g. goal distortion, autonomy, accountability). Suggestions for future research are given.

***Panet-Raymond, Jean (1992). Partnership: Myth or reality? *Community Development Journal* 27(2): 156-165.**

This research done in the province of Quebec examines relationships between voluntary organizations and those organizations funded by the Ministry of Health and Social Services which are responsible for local community services (CLSCs) in the domain of services for elderly people living at home. The primary objective of this research was to evaluate various experiences of collaboration between CLSCs and local volunteer centres serving elderly people living at home and to identify lessons learned though an action research framework. The authors identify two 'archetypes' of collaboration which represent opposite ends of a continuum and which they label 'real partnership' and paternalism or 'pater-nariat.' The former is characterized by mutual recognition and respect for differences (including possibly origins, nature, mission, objectives, activities, resources, structure, contributions and acknowledgement that both are mutually essential. The latter is characterized by the presence of a dominant group (the CLSC) which recognizes the community and its groups only as they serve state agendas and policies. In these forms of collaboration, the community workers' role is to initiate and support

voluntary agencies that complement the CLSC's objectives. Often these voluntary agencies are actually created by the CLSC and serve as a vehicle through which to access new sources of funds. This article also includes a short section which describes the action research partnership involving 30 voluntary groups, CLSCs and university researchers.

Provan, Keith G and Sebastian, Juliann G (1998). Networks within networks: Service link overlap, organizational cliques, and network effectiveness. *Academy of Management Journal* 41(4): 453-463.

This research examined network characteristics among mental health service providers in three American cities. The authors did not explicitly state that some of the organizations were nonprofit or voluntary organizations, but as community agencies are known to have a high level of involvement in mental health, it seems reasonable to assume that voluntary organizations were involved in the networks. The study examines various network characteristics using software established for the purpose, and compared them to client outcomes in these three places. They indicate this is exploratory work, but suggest that it is close ties among a 'clique' of core organizations that is important, rather than network-wide connections, and that two examples of connections that are important are reciprocal referrals and case coordination links. Connecting at the level of direct service provider seemed important, as opposed to at the governance or administrative levels.

Sherwood, Kenneth B & Lewis, Gareth J. (2000). Accessing health care in a rural area: an evaluation of a voluntary medical transport scheme in the English Midlands. *Health and Place* 6:337-350.

This article describes the origins, governance and operations of a rural transport scheme in England and describes directly the relationships and roles of the statutory bodies and community agencies and volunteers. This initiative arose out of a community development initiative sponsored by the regional health authority which was designed to address the fact that there had been pockets of relative social disadvantage identified within the region. This observation was coupled with the increasing centralization of medical services into larger communities. The 'Rural Wheels' program (the focal initiative of this article) was one of six initiatives included in this community development project. Facilitation was provided by staff hired by the health region specifically to nurture and support community development activities, but the goal was to establish self sustaining community projects within three years. 'Rural Wheels' grew to be a program that is coordinated by two elderly volunteers, and the volunteer drivers are, for the most part, also retired. Resources other than program operations personnel (who were all volunteers from the community) were contributed by community agencies – two parishes (financial contribution), county council (financial grant) and the medical centre (meeting room). The sustainability of the program is not clear. Some of the issues identified within the initial three years are: 1) the broadening of the activities beyond 'medical' (typically ride to doctors office) and toward 'health' (ride to visit ill husband, giving child a ride to activities when mother is ill), 2) continued financial commitment of county council as they are relatively uninvolved in service, 3) ability to recruit a new

supply of volunteers, given the ages of initial group, 4) concern that service is being exploited by health system (such as when ill patients are being transported by volunteers).

Snavely, Keith & Tracy, Martin B. (2000) Collaboration among rural nonprofit organizations. *Nonprofit Management and Leadership.* 11(2):145-165.

This article reports on research which included a mail survey of 292 rural nonprofit organizations in 13 counties in Illinois and Mississippi, in-depth interviews with selected individuals and focus groups. The sampling frame was not explicitly stated, but it appears as though all nonprofits in the counties were included, regardless of the substantive focus of their activities (e.g. health, housing, social issues). They focused on four types of collaboration: case management, community planning, organizational integration and interorganizational planning. The most common type of collaboration was in case management, with predominant activity being referral and sharing information with other organizations. Community planning and community issue assessment were also reported by 2/3 of the agencies. With respect to organizational integration, the survey showed that some types of integration, such as sharing of space, volunteers, grant writing and joint membership in umbrella organizations was quite common but other types of integration (e.g. shared staffing, joint budgeting and purchasing, and pooling of finances) was less common. Interorganizational planning (including such things as adoption of common guidelines and service procedures) is least common with only one-third of nonprofits reporting. Collaboration by nonprofits was more likely to involve other nonprofits, but collaboration with government agencies was also observed. Because of the broad sweep approach in the research, it is not possible to make definitive statements about relationships between nonprofits and statutory agencies per se.

***Watson, Roy E.L. (1982). The Adjustment of a National Voluntary Association to Change in its Environment: The Case of the Canadian Mental Health Association. *Canadian Public Policy* VIII: 4: 586-595.**

The effects of major policy decisions and changes in therapy for mental health in Canada in the early 1970's on the operations and governing structure of the Canadian Mental Health Association are described. In the mid 1960's, funding for health services (including mental health) was being transferred to the provinces under the auspices of the Established Programs Act, and gradually expertise and leadership for these programs migrated to the provinces. This led to a situation where the relevant health charity, which was active in communities (i.e. branches) emerged as wanting a stronger role in direct provision of services to former patients in their communities. The focus of this article is to describe the resulting organizational issues and changes within the CMHA in response to this shift to an emphasis on local service delivery within what had previously been a highly centrist organization with much of its activities focused at the national level. This case illustrates the impact of policy on operations of health charities in communities.

An Inventory of Voluntary Organizations Providing Health and Health-Related Services in Two Alberta Communities

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February 22, 2002

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The opinions expressed in this paper are those of the authors and do not necessarily reflect those of the sponsoring organizations.

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An Inventory of Voluntary Organizations Providing Health and Health-Related Services in Two Alberta Communities

INTRODUCTION

The provision of cost-effective health care in Canada is a topic at the forefront of public discussion and debate. Recently, the Canadian Premiers held a special conference to discuss the future of heath care and to plan strategies and future directions. When we think of health and health care, many different people may have many different ideas. According to Miller, Farmer, and Clarke (1994), the classic conceptualization of health offered by the World Health Organization (WHO) includes complete physical, mental, and social well-being. Similarly, Hancock, Labonte and Edwards (1999) take the view that health is much more than the measurement of death, disease and disability; it also encompasses mental and social well-being, quality of life, life satisfaction and happiness.

In Canada, as elsewhere around the globe, when we speak of health and health care in such broad-based terms, it is unclear where the lines of responsibility begin and end. According to Hart (1987) the voluntary sector and the government share the need for strong communities in Canada of many kinds – business communities, geographical communities, and social communities. Voluntary organizations represent alternatives, options, experimentation, supplementation, and leadership in the provision of various services and support mechanisms (O'Connell, 1996). There are many roles that voluntary organizations play, including providing services, and acting as vehicles through which the government fulfills some of its public responsibilities. It has also been suggested that the largest contribution is the independence voluntary organizations provide for innovation, advocacy, criticism, and where necessary, reform (O Connell, 1996).

Despite the recognition of the central role that voluntary organizations serve in promoting the health of Canadians, very little is known about the breadth and scope of services that voluntary organizations actually provide (Birdsell, 2001). The purpose of this research is to begin to develop an understanding of the contributions of voluntary organizations to the health of Canadians by undertaking an inventory of the types of organizations that exist, and the types of services they provide. This project begins on a small scale, by examining the voluntary organizations that provide health and health-related services in two communities in southern Alberta – one urban community (Lethbridge, population 70,000) and one rural community (Taber, population 7,000).

The Increasing Role for Volunteers and Voluntary Agencies

One of the foundational principles central to the health care system in Canada is that of universal access. Given the cultural and geographic diversity of Canada, it would appear to be a significant challenge to provide similar services and equitable access to services in all regions of the country. It is a further challenge to provide services in a cost-effective

manner in regions that do not have a population base that will support infrastructure such as clinics, hospitals and drop-in centres, or personnel in the form of practitioners in a wide variety of disciplines.

In the province of Alberta, public consciousness has been raised regarding the issue of access to services as a result of the implementation of a regional system for health and health care delivery. The regional delivery system was proposed in Alberta in 1994, and implemented in 1995. Through the reorganization of formal health care delivery, more than 200 local hospital boards were replaced by 17 regional health authorities and two provincial boards (The Alberta Cancer Board, and the Alberta Mental Health Board). While each region is relatively autonomous, there are provincial guidelines for levels of care. Smaller centres provide basic levels of primary care, larger centres provide more advanced levels of care, and the large cities (Edmonton and Calgary) provide highly specialized tertiary care facilities that provide advanced procedures such as open-heart surgery, advanced pediatric care, transplant services, and so forth.

The regionalization of health care delivery in Alberta creates two interesting dynamics regarding the role of volunteers and voluntary agencies. First, regionalization has been seen by many smaller rural communities as a move that has weakened local autonomy and decision making and has centralized many services to larger urban centres (Williams, et. al., 2001). This creates the potential for local volunteer agencies to play a more active role in providing or supplementing services that were previously provided locally through formal government programs and initiatives. Secondly, the move to regionalization has been utilized as a means to promote fiscal responsibility and rational business planning (Reay, et. al., 2000). The net result in many communities has been the reduction or elimination of services that were previously provided through the formal health care system but have been scaled back or discontinued for economic reasons.

An interesting research question then is the extent to which the types of services provided by volunteers and voluntary agencies differ between urban and rural centres. For example, are volunteers in rural settings more involved in the delivery of primary care services that were previously provided by professionals, while volunteers in urban settings are more involved in support activities? Or are rural volunteers more involved in driving people to the larger centres to receive service? At the present time, there is very little research that provides any indication of the types of services and the types of organizations that exist. For our purposes, we believe it is worthwhile to investigate and compare the types of voluntary organizations that exist in both urban and rural centres in order to gain an understanding of the similarities and differences. To do this, it is first necessary to develop a set of criteria or characteristics that can provide the basis for comparison and analysis.

CLASSIFICATION SYSTEM

For several decades now, sociologists and organization theorists have pondered questions regarding why there are so many different types of organizations, and have developed various criteria, methods, and techniques to categorize and analyze organizations (Pugh, et. al., 1968). Two approaches have generally been adopted: (1) taxonomies that seek to classify organizations based on the empirical establishment of observable characteristics, and (2) typologies that seek to classify organizations based on concepts or ideas developed by the researchers in generalized rather than specific terms (Miller & Friesen, 1984; Slack & Hinings, 1994).

Recently, efforts to synthesize the various approaches have resulted in the integration of various methods for classification and analysis. Greenwood and Hinings (1996) suggest that it is essential to explore both the structures of organizations and the systems and processes that connect the structural attributes. This suggests the need to examine and categorize both the structural attributes such as size, division of labor, and so forth, but also process issues such as development of a mission, decision making, governance, and ability to attract the necessary resources. These key characteristics can provide a basis for classification, analysis and comparison.

In searching the available literature related to voluntary health organizations, we found very little research designed to systematically classify voluntary health organizations. One exception is the work of Febbraro, Hall & Parmegiani (1999), which lays the groundwork for defining and classifying the voluntary health sector in Canada. An important contribution of this paper is the definition of what constitutes a voluntary organization. Febbraro, Hall & Parmegiani (1999), suggest that the voluntary sector is most appropriately defined as including both nonprofit and voluntary organizations. Following the work of Salamon and Anheier (1997), they identify five key defining characteristics of nonprofit/voluntary organizations: (1) they are organized; (2) they are private; (3) they are self-governing; (4) they do not distribute profits; and, (5) they are voluntary. Birdsell (2001) elaborates this criteria by explaining: "Conceptually then, organizations that are formally constituted to some degree, are separate from government, are equipped to control their own activities, do not distribute profits to their owners or directors, and involve some form of volunteer participation" (Birdsell, 2001:2). For our purposes, this definition appears suitable and appropriate to define the types of voluntary organizations that provide health and health-related services.

An additional definitional concern is to define the concept of *volunteer* as separate and distinct from *voluntary*. Formal volunteers may be simply defined as volunteers who engage in activities (volunteer work) under the auspices of some organization or formal group, such as a human service agency (Smith, 1985). The implicit assumption in this definition is that volunteer work is work which one does not receive financial compensation for performing. It is typically done out of some sense of community obligation or altruism, and may be thought of a work that is carried out as a result of intrinsic motivation rather than some extrinsic compensation or reward.

While the research on voluntary health organizations in limited, extensive research has been done on the organizational analysis of the voluntary sport organizations (Slack & Hinings, 1987, 1994; Slack & Thibault, 1988; Kikulis et al., 1992). There has also been significant research conducted on voluntary organizations that provide fire protection and emergency medical services in communities that do not have career service providers (USFA, 1995, 1998). While the research on volunteers in the emergency services has considered some organizational issues, the primary focus has been on the individual, in order to address issues related to the recruitment and retention of volunteers. This is an interesting area of research that could be used to inform research on the voluntary health sector; however, it is not the focus of the current research.

Our analytical concern is more at the organizational level and at the level of the defining and analyzing the population of organizations in this sector. This type of research has been conducted on voluntary sport organizations. Much of the research on voluntary sport organizations has been based on classical organization theory that focuses on the structural attributes of groups of organizations. For example, Slack and Hinings (1994) used the concepts of Standardization, Formalization, and Centralization as the basis for analysis to compare the structural patterns of 36 National Sport Organizations, and to longitudinally track organizational change. In the present study, our point of departure was to investigate, first and foremost, what voluntary health organizations do, and how they do it. Towards this end, measures of elements of structure were not considered to be as important as fundamental questions such as why the organizations exist, what kinds of services they provide, and how the services are provided. However, the extensive literature on the structuring of voluntary sport organizations can provide valuable insights on the unique nature of voluntary organizations, and can serve as an important and ongoing point of reference.

With specific reference to voluntary health organizations, Febbraro, Hall & Parmegiani (1999) suggest some basic principles around which voluntary organizations can be classified. These are the basis of the major area of activity, the beneficiaries of the services, the functions of the organization, the legal status of the organization, and the size according to revenue (Febbraro, Hall & Parmegiani, 1999:43). They further propose the adoption of categories developed by the United Kingdom Charity Commission. We question the applicability and utility of these categories in the Canadian context, and prefer to utilize more generalizable categories developed in mainstream organization theory through the study of for-profit, public sector, and nonprofit/voluntary organizations.

Using a more generalized approach, we focused on five fundamental aspects of voluntary health organizations to provide a basis for comparison. These were: (1) the basis for organizing; (2) the mission or purpose; (3) the types of services provided and methods of providing them; (4) internal processes and governance structure, and, (5) the methods of securing resources.

These five categories are based on the basic assumptions about organizations proposed in the widely accepted "open systems" model of organization (Scott, 1987). Key elements and assumptions in the open systems model are first of all that organizations are goal directed and exist to serve a function or purpose. Because of the unique nature of voluntary organizations, we have supplemented this category with the concept of "basis for organizing" to provide additional insight and clarity into the fundamental nature and purpose of the different voluntary organizations.

Proceeding from the initial assumption that organizations are goal directed and purpose oriented, the open systems model postulates three key areas of organizational activity: securing key *inputs* from the environment (examined here under the category "methods of securing resources"); *internal processes* (examined here under the category "internal process and governance systems"); and *outputs* (examined here as "types of services and methods of service delivery"). Each of these five categories we developed to guide our research is defined and explained below.

Basis for Organizing

Much of the work on developing classification schemes for organizations has been based on business enterprises operating under a profit motive. For voluntary organizations there are obviously many different reasons to exist, and this would seem to be a logical starting point for understanding and classifying various kinds of voluntary organizations based on their basis for organizing. Through our preliminary scan of organizations listed in local telephone directories and on local Web sites, we identified at least five different bases for organizing. These are (1) disease or clinical condition – many organizations are established around a specific disease or condition such as cancer, heart and stroke, diabetes, and so forth; (2) some organizations are built around the concepts of altruism and community service – examples would include the Kinsmen, Rotary, Lions, Elks, etc.; (3) some organizations are organized around Social Welfare, such as the Red Cross and the Food Bank; (4) some organizations are based on religion – this may include a specific church-based group or a broader denominational organizations such as the Salvation Army, Birthright, St. Vincent De Paul, and so forth; (5) the final basis we conceptualize as the basis for organizing is geographical – this would encompass a group that is brought together based on a defined geographic area or location such as community league, or neighborhood association. There may be organizations that are organized on the basis of more than one of these criteria, and there may be other bases we have not considered. Our research was designed to explore these issues empirically.

Mission or Purpose

Flowing from the basis for organizing is the notion of a mission or purpose. We are reluctant to theorize various categories a priori, but anticipate that there will be a relationship between the basis for organizing and the mission. Greenwood and Hinings (1988), suggest that perceptions of organizational purpose can provide key insights into the ideas, values and beliefs that shape the structures of an organization. Thus, our methods involve attempts to gain insights into the basic values and beliefs that shape the

organizations, as well as the structure designed to embody those patterns of values and beliefs. In addition to exploring conceptions of organizational mission or purpose, Greenwood and Hinings (1988) also suggest that insights will be gained by exploring the principles of organizing that provide an overall logic to the structural attributes, as well as the evaluation criteria used by the organization to evaluate performance.

Evaluation criteria is another area where the practices of voluntary organization are likely to depart from those of for-profit business enterprises. Criteria we have considered a priori include: number of volunteer hours worked; number of clients or customer served; budgets; fundraising targets or objectives; organizationally specific criteria; population health statistics or health indicators; and, volunteer retention/turnover. Again we do not see this list as exhaustive and intend to make provisions to generate additional categories if identified by the research participants.

Range of Services and Methods of Provision

In adopting a broad definition of health and health-related activities, there is a vast array of services that voluntary organizations may provide. These could range from traditional primary care activities, to counseling and support, to education and awareness, to advocacy, to general quality of life concerns.

Other issues that concern us include the basis on which a relationship is established between the voluntary organizations and consumers, clients or customers, and the way that services are delivered or provided. The establishment of relationships could be initiated by the client or customer, or could be sought out by the organization. The relationship could be established in a variety of ways from organizationally-driven programs such as mail-outs to target groups or populations, to client-driven mechanisms such as Web sites, hotlines and storefront operations.

Internal Process and Governance

We believe that an examination of internal process should begin with an examination of basic structural attributes such the number of paid staff and volunteers, number of board members, levels in the organization, and so forth. But we are also interested in the ways that tasks get accomplished and decisions get made. We are concerned with issues such as how volunteers are recruited, what types of incentives or reward programs are in place for volunteers, and how or whether performance evaluation is conducted.

Methods of Securing Resources

The final area we identified for exploration is the methods of securing key resources for the organization. We examined three important aspects related to this area: (1) human resources, defined in terms of paid staff, volunteers, and board members; (2) financial resources gained in terms of grants, donations, endowments, fees for services, and so forth; and, (3) relationships with other organizations. The issue of key resources is important both from a resource dependence perspective (Pfeffer & Salancik, 1978), and

from the point of view of identifying and understanding the relationship between government funding, government programs, and the operation of voluntary organizations that provide health and health-related services.

RESEARCH METHODS

The Research Sites

The City of Lethbridge has a population of about 70,000 people, and serves as the business hub of southern Alberta. The Chinook Health Region is headquartered in the City of Lethbridge, and it serves a population of more than 150,000 people spread over several hundred square kilometres including more than 20 small rural communities. The voluntary health sector plays an important role in Lethbridge and its surrounding communities. Within the city of Lethbridge there are more than 25 volunteer health organizations registered with an umbrella organization called "Volunteer Lethbridge".

These formalized volunteer organizations contribute to the health and well-being of the community and represent a vital piece of Canada's social, cultural and economic fabric. A spokesperson for Volunteer Lethbridge indicated that based on a survey conducted in 2000, involving 63 of their 79 member organizations, 358,124.6 hours of volunteering were recorded.

The identification of health and health-related organizations was based on our understanding of the organizations relative to our broad-based definition of health. Our definition of health extended along a continuum ranging from primary health at one end to quality of life at the other end. We considered the term *health* to apply to the community collectively as well as to individuals in the community. Thus, voluntary organizations that provide services to community (and not just to specific individuals) are included in our population of organizations.

The Town of Taber is a rural community located about 50 kilometers east of Lethbridge, and is comprised of approximately 7,000 residents. Taber has a local hospital that prior to regionalization was governed by a local board. The hospital as well as all other aspects of health in the community are now the responsibility of the Chinook Health Region (CHR) headquartered in Lethbridge. An interesting research question for us is how the services of voluntary organizations in these two communities (Lethbridge and Taber) are similar and different, and what relationship, if any, exists between voluntary agencies in the two communities.

In order to conduct such a comparative analysis, we set out to develop an inventory of volunteer health sector organizations in an urban centre (Lethbridge) and an inventory of volunteer health organizations in a rural centre (Taber). In each location we examined basic organizational issues such as how volunteers are organized and structured, what services/activities they carry out, and how they relate to other volunteers and voluntary organizations in the communities. We were specifically interested in the issue of the

impact that the shift to a regional model of service delivery by Alberta Health and Wellness has had on the delivery of health-related services by organizations in the voluntary sector, but this was beyond the scope of this initial study. Our starting point, and the emphasis of this project, was to develop an inventory of the formal organizations that comprise the voluntary sector in Lethbridge and Taber. In order to do this, we first developed the classification system outlined above, with the expectation that it could be used to characterize the various voluntary organizations that currently operate in each of the communities.

Data Collection

After initially conceptualizing the five organizational categories, we developed a series of open-ended questions that could be posed to key informants as a way to identify other issues that may have been overlooked. We developed a series of ten open-ended questions (see Appendix A) and identified eight key informants (see Appendix B) who were involved in work or research related to the voluntary sector in the greater Lethbridge area. The questions were posed to the key informants through various methods (e-mail, telephone, and face-to-face) and usable responses were received from six of the eight key informants identified.

Based on these responses, and the conceptual framework developed previously, we developed a questionnaire comprised of 18 questions. While many of the questions included categories that could be checked off by the researcher, we also included spaces for additional comments or categories that we may not have anticipated. This added an open-ended component to the questionnaire that reflected the exploratory nature of the research. The questionnaire was submitted to the University of Lethbridge Human Subjects Research Committee for review and approval. The questionnaire is included as Appendix C.

Using a variety of local resources such as the telephone directory, the Internet, and local newspapers, we attempted to identify all the organizations in Lethbridge and Taber that provide health and health-related services. Our list was expanded throughout the data collection process as some respondents identified additional organizations not included in our list. Our definition of health and health-related services was taken in a broad sense and conceptualized to include support activities and quality of life considerations. The point of contact for the various organizations was their published phone numbers. Contact with the organizations was initiated by members of our research team via telephone. The majority of interviews were completed over the telephone, although there were some respondents who asked that the questionnaire be faxed or e-mailed so that a written response could be provided. A complete list of organizations is provided in Appendix D.

RESULTS AND DISCUSSION

Through our investigation, 60 organizations in total were identified as the population of organizations. This included 46 organizations based in Lethbridge and 14 organizations based in Taber. We were successful in completing interviews with 40 of these organizations, which provided a response rate of about 67 percent. This included 9 out of 14 organizations in Taber, and 31 out of 46 organizations in Lethbridge. Questionnaires were not completed with some organizations as a result of messages not returned by the organization or because of no answer at the listed telephone number. Several attempts were made to contact each organization. Our initial analysis involves analyzing the data from the two communities in aggregate form in order to establish basic patterns at the population level.

Basis for Organizing

The categories we proposed as the basis for organizing were partially correct and partially incorrect. Disease-based organizations were the most common with 13 organizations reporting this was their primary basis for organizing. Ten organizations identified themselves as primarily social welfare organizations, while four said they were primarily service organizations. None of the respondents identified religion, geographic region, or culture as the primary basis for organizing. There were 13 respondents who indicated that the primary basis for organizing was something other than the six categories proposed. Responses given that fell into the 'other' category could be described as either proving specific services or providing social support. Specific services cited included community building, elderly, emergency medical services, first aid training, Handi-Bus, human services, liaison, need in the community, non-formal education, and safety in the community. Social support services included social support program, support for the inflicted, and wellness for women.

Based on the classification of the responses in the 'other' category, five categories can be derived: disease or clinical condition (13); social welfare (10); specific services (10); service clubs (4); and social support services (3). It is interesting that despite the societal shift towards a wellness model of health rather than a disease model, organizations based around specific diseases or clinical conditions remain the single most predominant organizational type. Taken collectively, however, the number of organizations in the other four categories is far greater than the number of disease-based organizations.

It is also interesting that the majority of organizations are organized around either a specific type of service delivery or some sort of general community service or support. Presumably, these organizations have emerged in response to a specific identified need or series of needs in the community that are not addressed by formal government programs or agencies. Many of the organizations identified the specific services and target clients groups in their mission statements. For example: "(We are) a home or support care provider to residents and their families"; "To take handicapped people and senior citizens to their destinations"; "To assist single native women, with or without children to adjust

to an urban lifestyle". These statements, and many others provided by the respondents, reflect missions designed to address specific needs in the community.

Insights into the basic assumptions about an organization and how and why it exists can often be gained by exploring how it is that the organization judges its performance (Greenwood & Hinings, 1988). We posed a specific question to the respondents in this regard. The overarching emphasis on service to the public or targeted user groups was reflected in the fact that the majority of respondents indicated that number of clients served was their key evaluation criteria. The frequencies of responses to the various alternatives are summarized in Table 1 below:

Table 1: Evaluation Criteria

Criteria	*Number of Organizations*	*Percentage*
Hours of volunteer service	11	27.5
Number of clients served	31	77.5
Staying within budget	20	50
Fundraising targets or objectives	13	32.5
Specifically established criteria	13	32.5
Population health statistics or indicators	5	12.5
Volunteer retention/turnover	8	20
Other criteria	11	27.5

Additional considerations identified in the 'other' category included number of minutes spent with clients, number of people trained, ask our customers, feedback from community, feedback from funding source, how many attend annual general meeting, profile in the community, and stability of the board.

Type of Services and Service Delivery

The categories we had identified as potential types of services proved to be useful in identifying the various activities of the organizations. The respondents were asked to identify all of the services provided and typically the organizations offered services in three of more categories. The categories we used in the questionnaire, and the number of responses we received, for each are shown in Table 2 below:

Table 2: Services Provided by Voluntary Organizations		
Service	***Number of Organizations***	***Percentage***
Diagnosis of illness or condition	1	2.5
Primary health care delivery	5	12.5
Support activities	16	40
Counseling and support	26	65
Health and wellness promotion	27	67.5
Prevention	22	55
Education	30	75
Advocacy	22	55
Research	7	17.5
Rehabilitation/adaptation	10	25
Palliative care	3	7.5
Community development	14	35
Quality of life	31	77.5
Referral services	25	62.5
Other	17	42.5

These results reflect the nature of the organizations as identified through the questions regarding the basis for organizing. There is a much greater emphasis on health promotion and support than there is on primary health delivery and diagnosis of illness or conditions. Services related to enhancing quality of life was the most frequently cited service (77.5%), followed by education (75%) and health and wellness promotion (67.5%). The results show that the voluntary sector is playing a major role in providing services and support to help individuals obtain information and support that is necessary to sustain a healthy existence. The provision of these types of services would seem to reflect the societal trend towards greater emphasis on prevention, education and wellness.

There were also services identified that respondents viewed as not fitting within the categories listed above. Other services identified included employment support, facilitation services, food giveaway, friendship, helping adults with disabilities, helping meals on wheels, needle exchange program, network services for families, outdoor youth programs, practicum opportunities, providing hot meals, providing rides for the disabled, and providing social programs. We also recorded the specific missions stated by each organization. These responses, and responses to other open-ended questions, are summarized in Appendix E.

Another aspect of our research was to explore how the services identified above are actually delivered. Again we proposed a number of potential methods, but also included an 'other' category to capture additional methods that we may not have considered. Respondents were allowed to select more than one way of establishing relationship, and many of the organizations indicated that they use more than one method. These results

indicated that the services the organizations provided are primarily demand driven, with the most frequently cited method for service delivery being by request from the client, customer or user of the service (85%). The frequencies of the various responses are shown in Table 3 below:

Table 3: Types of Service Delivery Methods

Mode of Service Delivery	*Number of Organizations*	*Percentage*
Face to face delivery	24	60
Delivery by request	34	85
Door to door	7	17.5
Lectures/seminars	23	57.5
Telephone inquiries	21	52.5
Hotline or distress line	5	12.5
Internet	15	37.5
Written materials – displays	29	72.5
Written materials – mail-outs	27	67.5
Media – TV/Radio/Newspaper	31	77.5
Other delivery methods	13	32.5

The role of voluntary organizations as sources of information, awareness, and educational material, is highlighted by the fact that written material is used by the majority of the organizations in the form of displays, mail-outs and use of media advertising.

Other methods of delivering services identified by the respondents included hosting community events, running contests, providing toll-free information line, and word of mouth. It is interesting that the Internet is used by only a small percentage of the organizations (37.5%). This could be related to start-up costs and efforts as well as the necessity of ongoing maintenance. The majority of the organizations who indicated that they had a Web site were large national organizations that had the Web site operated and maintained by a regional or national office and did not control it locally.

A related area of interest was how the organizations established a relationship with clients, customers or service users. Again, an overwhelming number indicated that the relationship was typically initiated by the user, reiterating that these organizations are often driven by demand. The frequencies of responses to this question are shown in Table 4 below:

Table 4: Methods of Establishing Relationship With Client		
Method	*Number of Organizations*	*Percentage*
Initiated by service provider	17	42.5
Initiated by service user	37	92.5
Provided to target groups	13	32.5
Provided on a broad basis	9	22.5
Targeted by demographic groupings	8	20
Targeted by geographic region	8	20
Other methods	7	17.5

In addition to the methods we had identified, methods included in the 'other' category included referrals (five responses) and word of mouth (two responses). This highlights the networking aspect of voluntary organizations wherein different organizations are aware of the services that others provide, and will steer users to the appropriate organization to have their needs addressed.

Internal Processes and Governance

The scope of the organizations was evaluated on the basis of five different categories: local, regional, provincial, national and international. The respondents had the ability to provide more than one response, recognizing that many organizations may be a local chapter of a larger organization. The most frequent response to this question was regional (17), followed by local (11), national (10), provincial (4), and international (3).

In terms of legal status, there was only one organization that identified itself as for-profit. The other 39 organizations were non-profit, with a variety of legal arrangements such as registered societies, charitable foundations and so forth. There was not one clear model or legal status that emerged, but rather a variety of different arrangements. All but three of the organizations reported having some sort of paid staff. Paid staff positions were typically an executive director or office manager who coordinates the day-to-day affairs of the organization and supports and facilitates the efforts of volunteers. One respondent commented that without a paid position, the organization would not continue to function as the paid staff recruited volunteers and coordinated their efforts.

Decision making within the organizations was evaluated to establish how routine day-to-day decisions affecting local operations were typically reached. The board of directors was the most frequently cited decision-making body, followed by the local staff and/or executive director. Individual volunteers did not appear to be empowered to make decisions, nor did local presidents. Presumably, the decisions made by the boards were communicated clearly to provide guidelines and directions for the volunteers. This is an area where further, more in-depth research could provide additional insights.

The number of volunteers, paid staff and directors in the 40 organizations in Lethbridge and Taber is summarized in Table 5 below:

Table 5: Number of Paid Staff, Volunteers and Directors in 40 Voluntary Organizations

Statistic	# of Paid Staff	# of Volunteers	# of Directors
Mean	10.11	242.48	8.13
Median	3.00	37.50	8.00
Mode	1.00	20.00	10.00
Std. Deviation	25.51	701.55	3.74
Range	0 – 140	0 – 4000	0 – 17

Methods of Securing Resources

The data and discussion presented above relates to the services that voluntary organizations provide and how they provide them. An essential aspect of service delivery is having the human resources necessary to provide the services required. We explored this aspect of voluntary agencies by first seeking information about the types of contributions that volunteers make. Time and expertise were the most frequently cited responses. A number of respondents elaborated on the importance of expertise relating to organizational, administrative and governance issues. A number of respondents referred to the importance of having volunteer board members who are competent decision makers committed to "doing the right thing". The frequencies of the various responses regarding volunteer contributions are shown in Table 6 below.

Table 6: Contributions by Volunteers

Type of Contribution	*Number of Organizations*	*Percentage*
Specific services	20	50
Time	38	95
Money	27	32.5
Expertise	32	80
Products (t-shirts, coupons etc.)	11	27.5
Cause related marketing	9	22.5
Data management	15	37.5
Resource centre	11	27.5
Equipment	17	42.5
Attending fundraisers and events	19	47.5
Use of home or office	14	35
Canvassing	8	20
Other ways	5	12.5

The five responses recorded in the 'other' category could all be considered additional forms of expertise as they included building houses, food management, program assistance, strategic planning, and governance.

Human resources are essential for voluntary organizations to operate, but so too are financial resources. The next area we looked at was the sources of funding that support the operation of the various voluntary organizations. The frequencies of responses are shown in Table 7 below.

The two most frequently cited responses were individual donations (72.5%) and fundraising (70%). In our key-informant interviews prior to the administration of our questionnaire, we were told that voluntary agencies were typically reluctant to provide detailed financial information, and thus we did not ask for a breakdown of the percentage of funding received from the various sources. In future research, this would be interesting to explore, in order to examine the relative contributions from the various sources. In terms of the frequency values, it is interesting to note that regarding government support, provincial funding is the most commonly cited followed by municipal and finally by federal.

Table 7: Funding Sources for Voluntary Organizations

Funding Source	***Number of Organizations***	***Percentage***
Donations from individuals	29	72.5
Endowments	8	20
Foundations	8	20
Municipal grants	12	30
Provincial grants	20	50
Federal grants	10	25
Corporate contributions	15	37.5
Contracts	9	22.5
In-kind donations	15	37.5
Fundraising	28	70
Other organizations	17	42.5
Other sources of funding	16	40

Additional sources of funding identified by the respondents included running concessions, crafts sales, gaming, garage sales, membership fees, memorials, owning revenue property, room and board, and selling products.

Affiliations and linkages was the third area examined under the heading of methods for securing resources. Only 18 of the 40 organizations indicated that they have formal (i.e., contractual) arrangements with other organizations. Those who did have formal arrangements typically had them with more than one other organization. Formal

arrangements with government were indicated by 11 organizations. More organizations (18) indicated that they had formal arrangements with other voluntary organizations, while 12 indicated they had formal arrangements with institutions, and two indicated they have agreements with corporations.

Examples of arrangements with institutions were Extendi-care having a contract with the Chinook Health Region. Other examples cited were having agreements to place practicum students from Lethbridge Community College. An example of an arrangement with another voluntary organization was Taber Handi-Bus, which has an arrangement with the Special Needs Society to provide service to their members. The most frequently cited other organization was Volunteer Lethbridge, which is an umbrella organization designed to coordinate the efforts of various volunteer agencies and provide centralize support services such as volunteer recruitment and advertising. An example of a corporate linkage was the Kidney Foundation which, through its *Cars for Kidneys* program has an arrangement with a local auto wrecker to tow away unwanted cars. The corporation (auto wrecker) pays the value of the car to the Foundation, and a tax receipt is issued to the donor of the car.

In addition to the formal arrangements outlined above, all the organizations indicated that they have some informal arrangements involving referrals, and networking with other voluntary organizations. The examination of specific linkages and interactions between voluntary organizations in the two communities was beyond the scope of this initial study, but is an area where additional research would be valuable in helping to understand the influences of the regional delivery of formal health services.

Comparison of Lethbridge and Taber

When comparing the organizations in Lethbridge and Taber, one sees there are a number of parallel types of organizations in the two communities, as well as some unique aspects of each. Parallel organizations, or those represented in both communities, included Alcoholics Anonymous, senior centres, food bank, hospital-based volunteer centre, special needs society, suicide prevention line, family support services, counseling services, Handi-Bus, and safety association. In Lethbridge there are many organizations that are regionally based and although they are located in Lethbridge, they provide service to the surrounding area, including Taber. This included all of the organizations that are based on a disease or condition (for example, Canadian Diabetes Association). Many of the nationally based organizations had a regional office based in Lethbridge. There was no consistency in the ways that the various organizations designated their regions. The majority served regions that extended west to the British Columbia border and south the United Sates border. However, the boundaries to the north and to the east varied tremendously. With the exception of the two hospital-based organizations, none of the organizations described their service area as being the formally defined as the regional health authority (Chinook Health Region).

There were three organizations that were identified as being unique to Taber. The first was the volunteer fire department. Since Lethbridge has a full-time paid fire department, there was no similar volunteer organization in Lethbridge. One month prior to the commencement of our research, the Taber Fire Department provided Emergency Medical Services (EMS) by utilizing volunteer care providers. As of January 1, 2002, however, the Town moved to a full-time paid ambulance staff. This change reflects a trend found throughout North America that is related to the increased training demands for firefighters and paramedics, and well as the difficulties in recruiting and retaining qualified volunteers (USFA, 1995, 1998).

Another organization unique to Taber was *Touch of Taber*. This organization stated its mission as "making Taber a pleasant welcoming place". While there is some similarity between this organization and Welcome Wagon in Lethbridge, Touch of Taber has a mandate that extends to visitors and not just to people moving into the community. The organization works to maintain the "small-town atmosphere" and strives to make the community a place that is warm and friendly. This is an example of a voluntary organization whose efforts are focused on the health of the community as a whole rather than on individuals.

The Lions and Lioness Clubs were also unique to Taber. While Lethbridge has many different service clubs such as Rotary, Eagles, Shriners, and Downtown Optimists, the Lions and Lioness organizations are unique to Taber and do not have chapters in Lethbridge.

Overall, there was no unique or discernible pattern that would allow us to conclude that the two communities were fundamentally different in the types of organizations that exist and the types of services they provide. In both communities the organizations appeared to be driven by the existence of specific needs that required attention. These include such basic necessities as food for those who do not have enough (food banks), seniors' associations, and transportation for persons with special needs (Handi-Bus). By focusing primarily on formal organizations, our current research did not delve into the acquisition of services from the consumers' point of view. Our suspicion is that many of the primary health services, and access to those services through driving and helping make appointments and so forth, are obtained through the informal networks of family and friends. Further research that focuses on the consumers' point of view, could provide rich and meaningful insights into the distinctions and differences between urban and rural communities.

SUMMARY AND IMPLICATIONS

This research was designed to provide some preliminary insights into the scope and breadth of the voluntary sector as it relates to the provision of health and health-related services. While there are a plethora of classification systems and theoretical approaches for the analysis and comparison of for-profit organizations, there has been little research conducted on the voluntary sector, with the exception of the work done on voluntary

sport organizations by Slack and Hinings and their associates. In this research we have tried to theorize organizational characteristics that are observable and analyzable, and that will provide some meaningful basis for comparison. Our empirical approach has been primarily descriptive and included an open-ended component to allow us to develop emergent categories. Through our research we have established some criteria for comparison and have provided data based on two communities in southern Alberta. While our ultimate goal is to provide some comparative analysis between an urban setting and a rural setting, this initial analysis has looked at the data primarily in aggregate form to establish patterns and trends, and to test the appropriateness of our classification scheme.

Some of the traditional criteria for the comparison of organizations, such as formalization, centralization, and so forth, are less relevant for voluntary organizations that are typically informally structured and have diffused decision-making structures. Here we have focused more on fundamental and foundational concepts such as basis for organizing, types of services, and methods of service delivery. This approach has been useful in our preliminary descriptive analysis and suggests that future research in this view would be valuable. For example, in our initial search we did not find any organizations that were geographically based. Later in the study we did identify one tenants' association. While neither Lethbridge nor Taber are formally organized into neighbourhoods or communities, other cities are. The City of Edmonton, for example, has a well-defined and established community league system that provides the organizational basis for many community programs and activities. It would be interesting to conduct systematic research in other centres to explore the extent to which the characteristics found in this study are unique to southern Alberta or generalizable to other regions of Canada.

In considering the basic characteristics of voluntary health organizations identified in this research, there are some marked differences from the findings reported on voluntary sport organizations. In their longitudinal study of organizational change in National Sport Organizations, Slack and Hinings (1994) explored the concept of isomorphism and used institutional theory and resource dependency theory to explain why many organizations exhibited similar organizational characteristics. They characterized change as involving a movement towards an organization design type they termed the *professional bureaucracy* (see Mintzberg, 1983 for a description). They further observed that the movement towards this type of structuring involved a shift in the power structures and decision making with the nexus of authority shifting from the hands of volunteer board members to those of paid professional staff members. They further noted that one of the major forces driving the change in organizational structures and processes was government funding and the administrative requirements, such as long-range strategic planning, that were associated with successfully obtaining and maintaining ongoing funding.

There are some fundamental differences between the approach taken by Slack and Hinings (1994) and our approach to voluntary health organizations. Their study focuses on national organizations while ours focused on local and regional organizations. Their study was longitudinal, while ours was cross-sectional. Their study used scales to

specifically measure, analyze and compare organizational characteristics, while our study sought primarily to describe the various characteristics. Nonetheless, there are some important comparisons that can be drawn from the two studies.

First, the overarching influence of institutional forces that was observed by Slack and Hinings was not apparent in our research. While the organizations Slack and Hinings studied all received a major portion of their funding from a single source (Federal Government of Canada), the organizations in our study received their funding from a wide variety of sources (see Table 7). The organizations, taken collectively, did not appear to be overly influenced by a common funding source or external influence. The most frequently cited source of funding was individual donations, and thus the organizations were less accountable and less influenced by a common funding agency. While we did not ask for a specific breakdown of the percentage of funding received from each source, we did ask which source was deemed to be most important. Fundraising campaigns (i.e. the systematic collection of donations) was the most frequently chosen response.

That is not to suggest, however, that they were completely free from any outside influence. In responding to the question regarding evaluation criteria, "feedback from funding source" was cited by two different organizations. The wide variety of other types of evaluation criteria reflects a diversity in approach, and far less homogeneity and standardization across organizations than observed in voluntary sport organizations. This is encouraging considering the suggestion that one of the strengths of the voluntary health sector is its ability to be creative and innovative (O'Connell, 1996). In the national sport organizations, standardized methods and formalized procedures were an essential part of the movement towards a professional bureaucracy (Slack & Hinings, 1994). No such trend was observed in the voluntary health sectors as paid staff seemed to have a variety of backgrounds and approaches, and did not share the ethos of professional administrators described by Slack and Hinings (1994).

The less formalized and more loosely structured approach taken in the voluntary health sector was characterized by a paid staff member in one of the organizations as being analogous to a weekend camping trip with a group of friends. He suggested that on a camping trip one person brings the water, different people bring different varieties of food, someone chops the firewood, someone builds the fire, and someone sets up the tent. Everyone contributes in his or her own way, and it is not necessary or feasible to try to account for each person's relative contribution. Similarly, in a voluntary organization, he suggested, everyone contributes based on his or her own talents, abilities, and preferences, and there is no attempt made to keep an account or ledger of the various contributions. He further suggested that the effort required to try to keep track of things would take time and energy away from providing services. Thus, he believed that individual talents and energies were better spent on actually providing services than on developing unnecessary administrative procedures.

This approach is very different from the professional bureaucratic approach found by Slack and Hinings (1994). We must bear in mind, however, that they examined large national organizations, while our focus was on local and regional organizations. It may well be that at the national level there are large highly organized voluntary health agencies that approximate the professional bureaucracy model of organizational design. There were some indictors of this found in our literature review. For example, an article that appeared in the *Toronto Star* suggests that voluntary health organizations such as St. John Ambulance and the Parkinson Foundation of Canada must be run like businesses in order to be successful (Scrivener, 1999). The article further states that "those who run non-profit organizations are taking additional training at business schools. They are working on their Masters in Business Administration degrees to help them run their organizations more efficiently in an era of cutbacks and increased competition for charitable donations" (Scrivener, 1999). While we did not see any strong evidence of this trend in our research, we did find that paid staff were employed by at all but four of the organizations studied, and seemed to be an essential part of many organizations.

Another interesting way that voluntary organizations are influenced by professional practices is through practicums and young volunteers seeking to build their résumés by gaining experience in voluntary agencies. Two of the organizations in the study referred to the fact that practicum programs with educational institutions were a source of volunteer expertise. For young job seekers, work experience is often a prerequisite for finding paid employment. Volunteering is a way to gain experience in areas such as management and administration, bookkeeping and accounting, marketing and fundraising. Through this trend, there is the propensity for the latest theories and methods being taught in educational institutions to be transferred and applied to the practical day-to-day operations of voluntary organizations. In this regard, voluntary organizations are not only a means for the transmission of existing institutionalized practices, but they also have the potential to be conduits for change through the application of new ideas and practices.

The movement of the majority of the voluntary sport organizations towards the professional bureaucracy model was explained by Slack and Hinings (1994) in terms of institutional forces and isomorphic pressures. These are the social pressures to take on a defined set of organizational characteristics and practices that are institutionally accepted in that organizational sector. Clearly the pressures to become more bureaucratic are not restricted to the voluntary sport sector, and are pervasive in all walks of life (Weber, 1947). However, our initial findings suggest that institutional forces are not anywhere near as pervasive or influential in the voluntary health sector as they are in the national sport organizations sector. There are general indicators of the influence of institutional forces, however, such as the fact that all of the organizations in the study had formal mission statements that provided them with a sense of purpose and legitimacy.

The other interesting finding in the Slack and Hinings (1994) research is the active resistance to change found in some organizations. This was observed even in situations of high resource dependence and the strong potential for the exertion of coercive pressure, and was found to be most prevalent in organizations where institutional norms conflicted

with the prevailing values within the organization. A similar finding was demonstrated by Smith and Sosin (2001) in their study of faith-related agencies. They found that voluntary agencies were loosely coupled to faith in terms of resources, and more tightly coupled in terms of authority. These findings all suggest the need for further research to explore the values and beliefs held by a wide spectrum of respondents (both paid staff and volunteers) within each voluntary health organization.

In the voluntary health sector, where resource dependence relates to a broad range of individuals rather than a common funding agency, there is much more potential for freedom of expression and broad diversity in organizational form and function. The lower level of institutional influences, as well as the greater propensity for resistance to institutional pressures, are two explanations for why there was far less homogeneity in the voluntary health organizations studied here as compared to the voluntary sport organizations studied by Slack and Hinings (1994).

Limitations

There are many obvious limitations to this research. First, while we set out to define and examine a population of organizations, we were not successful in gathering data from all 60 organizations identified. While it is our belief that the approximately 67 percent response rate is relatively representative of the entire population, there is no way to ensure this. Further, since different organizations have different legal status and mandates, there is no centralized information directory or database that could be referenced or consulted to ensure that we had identified all of the appropriate organizations. We relied on a number of different information sources, including subject matter experts, but there is still no way to ensure that our list of all organizations in the population, as we have broadly defined it, is comprehensive and exhaustive. Through the process of sharing our initial findings with stakeholders, a number of additional organizations were identified and added to our list (see Appendix D).

Secondly, our analysis relies on a single source of information in each organization. While we made every attempt to seek out representatives who were knowledgeable about the organizations, each represents one point of view that may not be shared entirely by all members of the organizations. The vast majority of respondents (36/40) were paid employees who represented a particular point of view.

Thirdly, as noted above, the data we collected in this study was gathered from research sites in Lethbridge and Taber. While it is our ultimate aim to compare the voluntary organizations in the two communities, this initial paper was designed simply to test our assumptions about classification criteria, and to collect preliminary data. Consequently, the data from the two communities are presented primarily in aggregate form and do not provide the basis for extensive comparative analysis. That will be one of the subjects of our ongoing research and future publications.

Future Research

This paper has attempted to lay the groundwork for the development of an understanding of the types of organizations that provide health and health-related services in Canada by looking at two communities in southern Alberta. Basic criteria for comparing organizations were developed around basis for organizing, types of services, types of service delivery, internal processes and governance, and methods of securing resources. These categories provided insight into the types of organizations that exist and the types of services they provide. The research has suggested that the majority of organizations are driven by demand, or the need for services, in their respective communities. As the ongoing public policy debates about health and wellness in Canada and abroad continue to percolate, knowledge about the voluntary sector and the types of services it provides are essential.

This research has focused on formal organizations that have some sort of structure and legal status. In the course of this research many people have observed the role that individuals and informal organizations also play. Most notable are the individual friends and family members who are often called upon to help people in need. This is an entirely different aspect of the voluntary sector that is also worthy of research attention. The continuation of the work that has been initiated through this project, as well as the expansion of the research to include consideration of individuals and informal networks, are essential next steps to expand our knowledge and understanding of the increasing role of the voluntary sector in the provision of health and health-related services in Canada.

As noted previously, this study was localized to southern Alberta, and may not be representative of other regions in Canada. Further research in other centres would be helpful and could provide the basis for comparative analysis. It may be beneficial to target other specific regions – for example, areas that have formalized community structures (such as Edmonton), and other provinces that do not have their formal health systems organized on a regional basis.

APPENDIX A: Key Informant Interview Questions

Introduction

We are conducting research designed to develop an inventory of volunteer organizations that are active in the areas of health and health related services in Lethbridge and Taber. We understand that you have some knowledge and understanding of the voluntary sector and would appreciate it if you could share your opinions with us by answering the following questions.

1. What health and health related services are provided by volunteers?
2. Do you know of any data bases or directories that would list voluntary organizations?
3. Would you be able to estimate the size of the volunteer sector in Lethbridge and Taber, and the percentage that would be involved in health and health-related services?
4. Would you be able to translate that estimate into person-hours per month?
5. Do you think that the number of people in the voluntary sector has been growing or declining in the past 10 years? (please explain)
6. Do you have any sense of who volunteers? (demographics and percentages)
7. What do you think motivates people to volunteer?
8. Why do you think people would volunteer in the health and health related sectors rather than other volunteer sectors such as youth sports?
9. Our current research focuses on formal organizations, but we know that there is also a significant amount of volunteer work that is done informally and individually. Do you have any insights or comments regarding informal volunteer networks?
10. Do you have suggestions regarding methods for researching the informal voluntary sector?

We would appreciate if you could provide your written response via email to b.williams@uleth.ca . If you would prefer to respond to these questions verbally, we would be pleased to arrange a personal interview or telephone interview with you. Please e-mail us back to indicate that preference, or call us at (403) 329-2068.

Thank you for your input, it is much appreciated!

APPENDIX B: List of Key Informants by Position/Organization

- Volunteer Coordinator, City of Lethbridge Volunteer Services
- Researcher, Faculty of Social Work University of Calgary
- Volunteer Coordinator, Chinook Health Region, Lethbridge
- Volunteer Coordinator, Volunteer Lethbridge
- Town Planner, Town of Taber
- Researcher, Faculty of Health Sciences, University of Lethbridge
- Researcher, Faculty of Management, University of Lethbridge
- Volunteer Coordinator, Chinook Health Region, Taber

APPENDIX C: Questionnaire Used to Survey Organizations

Inventory of Voluntary Agencies Providing Health and Health Related Services

Date:
Time:
Organization:
Spokesperson:
Researcher:
Telephone___ or In-person____

Hello, my name is _____ I am a researcher with the University of Lethbridge. We are conducting research that is funded by Health Canada. The research is designed to develop an inventory of the various voluntary organizations that are involved in the provision of health and health related services in the greater Lethbridge area.

Our survey consists of 18 questions and will take approximately 15 minutes to complete. Your participation is entirely voluntary and you may choose to stop the interview at any time.

The results of this research will be published in a research paper that will report the findings in aggregate form. Are you willing to proceed with the interview?

Note to interviewer: Do not read aloud the words appearing in brackets. They are for your attention only or for prompting in the event the participator does not understand the question.

(Please read Question # 1. Your goal is to check off any category mentioned by the respondent)

1) First, we would like to get a general idea concerning the basis for organizing. Please indicate which of the following categories best classifies your basis for organizing.

- ☐ Disease of clinical condition (i.e. organized around a specific disease such as Heart Foundation, Diabetes, cancer, etc)
- ☐ Community Service Clubs (organized around community service such as Rotary, Kinsmen, Lions, etc)
- ☐ Social Welfare (organized around helping others such as red cross, salvation army etc.)
- ☐ Religious (Denominational or church-based such as Catholic Social Services)
- ☐ Geographic (based in a specific geo region, eg Southern Alberta Seniors club)
- ☐ Cultural
- ☐ Other _____

(Interviewer, this part 2 is only if they checked off more than 1 response)

Please explain which category is the primary reason for organizing and why?

_____

_____

2) What is your legal status (or your official designation)?
Please indicate which best explains your legal status. As I read each category, please tell me which one applies to your organization:
(READ THE ALTERNATIVES)

- ☐ For Profit with paid staff
- ☐ Non-profit with paid staff
- ☐ Non-profit, volunteer-run
- ☐ Charitable foundation
- ☐ Registered Charity
- ☐ First Nation Organization
- ☐ Registered society
- ☐ Purely volunteer
- ☐ Club or loose affiliation (not officially registered/recognized status)
- ☐ Other _____

3) What is the overall purpose or mission of your organization?

_____

_____

Do you have a formal mission statement you could send us by fax or mail?
Yes____ No____ (Our fax number is 329-2038)

4) What is your method of task accomplishment? In other words, how is work organized assigned or distributed and completed? (Researcher, you may prompt them with such answers as: the executive director handles the workload and then passes on tasks from there or each employee handles situations on their own, that is they are given autonomy to accomplish certain tasks)

_____

_____

5) Next, we would like to know about the size of your organization.
Number of paid staff_____
Number of volunteers_____
Number of directors on your board_____

Do you have an organizational chart that you could send to us by fax or mail?

Yes____ No____ (Our fax number is 329-2038)

6) The sixth question involves the types of services your organization provides. There are many roles that voluntary organizations play, therefore, please indicate to the best of your ability, which services your organization provides. You may

choose more than one. As I read each alternative, please tell me whether or not it applies with a yes or no answer. Does your organization provide:
(READ THE ALTERNATIVES)

- ☐ Diagnosis of illness or condition
- ☐ Primary health care (healing or helping the sick, treatment for disease, etc)
- ☐ Support activities related to primary health care (driving senior to appointment)
- ☐ Counseling and support
- ☐ Health and wellness promotion
- ☐ Prevention
- ☐ Education
- ☐ Advocacy
- ☐ Research
- ☐ Rehabilitation/adaptation
- ☐ Palliative care
- ☐ Community Development
- ☐ Quality of life (eg. healthy eating, personal fitness, environmental awareness)
- ☐ Referral services
- ☐ Other _____

(Interviewer, this part 2 is only if they checked off more than 1 response)
Please explain which service is the primary offering and why?

_____

_____

7) Next, it is important for us to gain an understanding of the manner in which your organization delivers its service and gets its message across to the general public. Please indicate which mode of service delivery your organization uses to accomplish its mission. You may choose more than one:
(READ THE ALTERNATIVES)

- ☐ Face to face direct delivery (home visits, hospital visits, seniors lodge)
- ☐ Delivery by request (some one calls your office or drops in)
- ☐ Door to door
- ☐ Lectures/seminars
- ☐ Telephone
- ☐ Hot line or distress line
- ☐ Internet
- ☐ Written materials – displays
- ☐ Written materials – mail-outs
- ☐ Media – TV and radio
- ☐ Other_____

Which method of service delivery do you feel is most central to your organization and why? And which group do you believe your services are targeted to (i.e. families, groups, couples, communities, organizations)?

_____

_____

8) We would like to find out the ways that volunteers contribute to your organization. Traditionally, the term voluntary sector indicated that effort came from volunteers-time, money, or materials, but in our study, we would like to find out if there are any new and interesting other ways that people contribute to the voluntary health sector. Please indicate the types of contributions you receive from volunteers by answering yes or no to each type. You may select more than one.
(READ THE ALTERNATIVES)

- ☐ Specific services
- ☐ Time (if yes ask for examples)
- ☐ Money
- ☐ Expertise
- ☐ Products (i.e. coupons, t-shirts)
- ☐ Cause Related Marketing (i.e. teaming up with a for-profit company)
- ☐ Data base
- ☐ Resource centre
- ☐ Equipment (i.e. computer, back-hoe, vehicle)
- ☐ By attending a fundraiser or a special event
- ☐ Use of home or office
- ☐ Canvassing
- ☐ Other _____

Which of these do you think is the primary source of contributions by volunteers? Please explain your choice.

9) Please outline the methods you use to attract volunteers and the incentive or reward programs you use to retain volunteers.

10) Please describe the basis on which you develop contact with or provide services to your clients or customers:

- ☐ Initiated by service provider (agency or individual)
- ☐ Initiated by client or service user (they phone you or drop in)

☐ Provided to specific target groups (eg hospital gives you a list of people at risk)
☐ Provided on a broad-basis (putting pamphlets in everyone's mail box)
☐ Targeted by demographics (eg specific groups such as teens or seniors or Mexican Menonites)
☐ Targeted by geographic region (i.e. a specific health issue only specific to Southern AB)
☐ Other _____

_____

11) Please explain the basis by which you evaluate your organization's performance.

☐ Hours of volunteer service
☐ Number clients served
☐ Budget (i.e. staying within budget plan)
☐ Fundraising targets or objectives
☐ Specific criteria
☐ Population health statistics or health indicators
☐ Volunteer retention/turnover
☐ Other

Of the choices you identified, which one is used as the primary basis for evaluating performance? And who decides the basis for evaluation criteria?

_____

_____

12) What is the scope of influence of your organizations?
☐ Local
☐ Regional
☐ Provincial
☐ National
☐ International

13) Who or what body in your organization has the authority to make decisions regarding local issues?

☐ President
☐ National Director
☐ Executive Director
☐ Board of Directors
☐ Local Board
☐ Local staff
☐ Volunteers
☐ Other _____

_____

14) What are the sources of funding that support the operations of your organizations?

- ☐ Donations (from individuals)
- ☐ Endowments
- ☐ Foundations
- ☐ Municipal Grants
- ☐ Provincial Grants
- ☐ Federal Grants
- ☐ Contributions (Corporate)
- ☐ Contracts
- ☐ In-Kind Donations
- ☐ Fundraising
- ☐ Other Organizations (i.e. United Way, Wild Rose Foundation)
- ☐ Other

Of the sources you identified, which two would rank as the most important? _____

_____

_____

_____

_____

_____

_____

15) Do you have explicit affiliations or alliances with other organizations such as institutions, government agencies and other volunteer agencies?

- ☐ With Government departments or agencies
- ☐ With corporations (sponsorship or endorsement program)
- ☐ With institutions or formal organizations (eg. Hospital, university, schools)
- ☐ With other volunteer agencies
- ☐ Others _____

_____

Are these formalized affiliations or agreements (that is, do you have a written contract that states so)?

Yes_____ No_____

16) What facilities are owned or operated by your organization?

- ☐ Office (rent or own)
- ☐ Storefront service (rent or own)
- ☐ Home-based offices
- ☐ Website (self maintained and operated?)
- ☐ Drop in centre (rent or own)
- ☐ Hospitals

☐ Clinics
☐ Others _____

17) Do you have an annual report, newsletter or other official documents you would be willing to share with us that would tell us more about your organization?

Yes____ No____

(If yes, make arrangements to have them picked up faxed or mailed)

18) Thank you so much for your participation, this brings our interview to a close. Are any other comments or issues you would like to raise that have not been addressed in the survey? (Record any comments)

Are you interested in receiving a copy of our report once the study is completed?

Yes_____ No_____

(If yes, get mailing address including postal code)

Thank you again for your participation!

APPENDIX D: List of Voluntary Health Organizations in Lethbridge and Taber

1) Canadian National Institute of the Blind (CNIB)
2) Lethbridge Food Bank
3) Extendicare/Lethbridge
4) Lethbridge Senior Citizen Organization
5) The Parkinson's Society of Southern Alberta
6) Alberta Association for Safety Partnerships (Taber)
7) Taber Handi-Bus (Taber)
8) Taber Volunteer Fire Department (Taber)
9) Interfaith Food Bank
10) Lethbridge HIV Connection
11) South County Treatment Centre
12) Birthright
13) Rehabilitation Society
14) Scouts Canada
15) Nordbridge Senior Citizens Association
16) Womanspace Resource Centre
17) Native Women's Transition Home Society
18) Touch of Taber (Taber)
19) Canadian Red Cross Society
20) Taber Special Needs Society (Taber)
21) Canadian Paraplegic Association
22) St John Ambulance
23) Safety City Society of Lethbridge
24) Schizophrenic Society of Lethbridge
25) Fibromyalgia and Chronic Fatigue Association
26) The Arthritis Society
27) Canadian Organization for Rare Disorders
28) VON Alberta South
29) Lioness Club of Taber (Taber)
30) Lethbridge Society for Meals on Wheels
31) Taber Food Bank Society (Taber)
32) Suicide Crisis Line
33) Canadian Cancer Society
34) Boys and Girls Club of Lethbridge
35) Alzheimer Society
36) Southern Alberta Epilepsy Association
37) The United Way
38) The Kidney Foundation
39) Lions Club of Taber (Taber)
40) Barons – Eureka Warner Family Support Services (Taber)
41) Alcoholics Anonymous (Taber)
42) Parkside Manor of Taber (Senior Centre) (Taber)
43) Taber Hospital (Volunteer Resource Dept) (Taber)

44) Canadian Diabetes Association
45) Lethbridge Hospital – Volunteer Division
46) Crohn's and Colitis Foundation of Canada
47) Girl Guides
48) Family Ties Association
49) Adult Children of Alcoholics &/or Dysfunctional Families
50) Friends in Recovery
51) Chinook Stroke Club
52) Alcoholics Anonymous (Lethbridge)
53) Brain Trauma Support Society
54) On our own
55) Taber Health Centre/Christian Counselling (Taber)
56) St Michael's Health Centre
57) Canadian Mental Health Association
58) Lethbridge Handi Bus Association 1904 13th Avenue North - Lethbridge Alberta
59) Southern Alberta Self – Help Association
60) Downtown Optimists of Lethbridge

Additional organizations identified after data collection process was completed:

Fraternal Order of Eagles
Lethbridge Shrine Club
La Leche League of Lethbridge
Rotary Club of Lethbridge
Big Brothers and Sisters
Brain Injury Association
Lethbridge and District Pro-life
Habitat for Humanity
Lethbridge Handicapped Riding Association
Loyal Order of Moose
Lethbridge Welcome Wagon
Parkbridge Estates Tenant Association

APPENDIX E: Qualitative Responses to Open-ended Questions

1) Canadian National Institute of the Blind (CNIB)

1. Disease of clinical condition: Could be from different causes, rather than just one cause
3. Purpose or mission: Ameliorate the conditions of blind and visually impaired persons and promote enhancement of sight
4. Task accomplishment: Receive referral, go through intake (locally within Lethbridge, George does this, he's the Coordinator of Community Services), referred to services offered within organization or by outside organization
Primary service provided: Rehabilitation is primary service because it is primarily offered only by us, no other organization or agency that provides this service
Service delivery that is central: One-on-one (face to face direct delivery) because to be successful one-on-one results in higher rate of success
8. Time: volunteer who reads mail to a client
Money: donate
Expertise: not at local level, happens at provincial level
Canvassing: not local
9. Methods to attract: enlist Volunteer Lethbridge to recruit
Incentives: Offer awards for volunteers, annually awards given, incremental awards given
Primary basis for evaluation: Combination of number of clients served and number of minutes spent with clients; decided provincially

2) Lethbridge Food Bank

3. Purpose or mission: Serve clients; raise money to purchase food to supply to people who don't have access to it
    - in the process of rewriting the mission statement and rewriting policies and procedures right now
4. Task accomplishment: Many tiers; paid staff, volunteers (bingos, special events, food hampers); tasks passed on to employees and volunteers
6. Primary health care: food
Support activities related to primary health care: driving hamper to homes
7b: targeted to community as a whole
8. Primary contribution of volunteers: Time and money - of the 85 volunteers the donation is time and money is a primary source of income
9. Methods to attract: volunteers seem to just come to us, grassroots, serve basic needs, community awareness is acute
Incentives: work environment is great, treat volunteers with dignity and respect
11. Primary basis for evaluation: In the past no formal evaluation, looking at it right now, basically don't want a lot of clients because then that means there is a lot of poverty; look at did we have enough food to serve clients
18. In dire need of food; poverty is high right now and struggling to provide the same quality of service as before

3) Extendicare/Lethbridge

3. Purpose and mission: Extendicare is a home or support care provider to residents and their family

4. Task accomplishment: Administrator, directors of care, therapy team, nursing aids, activity supervisor, office staff, social worker; there are routines and terms of reference for each department
5. Have an organizational chart, but cannot send it; have Regional Director, Administrative Director, and so on down (see Q4)
8. Time: volunteers assist with family members and other residents
Money: ladies auxiliary
Primary contribution of volunteers: Program assistance because all others are already provided one way or another; they provide a fresh face, bring uniqueness
9. Methods to attract: used to be member of Volunteer Lethbridge, but no more because for profit; most volunteers call in and are students looking for volunteer hours, or live in neighbourhood, or have family members here
Incentives: annually have volunteer appreciation; have volunteer recognition program; focus on daily gratitude, references provided
18. First bed available

4) Lethbridge Senior Citizen Organization

4. Executive director, has Assistant who is office manager, 2 portfolios which include activities and support services
6. Community Development: involved, but don't provide; community initiatives
Primary service provided: Tough to do, quality of life because part of mission is to provide best quality of life
7b: targeted to seniors
9. Methods to attract: volunteer questionnaire when sign-up, tables in centre, form on Internet, phone asking for volunteers
retention: Appreciation each year - dinner, tickets to a volunteer evening, coffee vouchers

5) The Parkinson's Society of Southern Alberta

3. Mission statement: To provide information and education regarding Parkinson's and related disorders, to provide support services unique to the needs of people with Parkinson's and their families, and to support research efforts for alleviating the effects of and discovering a cure for Parkinson's
4. Executive director, Board of Directors, Hired staff; have duties which overlap and specific roles - support services director, fundraising coordinator, volunteer program coordinator, counsellor, physiotherapist, office staff
7b: targeted to families mostly
9. Methods to attract: Get through contact with someone who has Parkinson's mainly; first hand, advertise
Incentives: feel connected because of cause, see the need for support, acknowledge through thank you and special events
11b: Primary basis for evaluation: decision by Board and Staff combined

6) Alberta Association for Safety Partnerships

3. Purpose and mission: To improve workplace safety in Alberta
4. One employee
7. b: targeted to workplaces
10. Methods to attract: don't know; people good about helping us, come to us
11b: Primary basis for evaluation: government decides basis for evaluation

7) Taber Handi-Bus

1. Other: Handi-Bus service
3. Purpose or mission: To take handicapped people and senior citizens to their destinations
4. People phone, make sure get picked up; no autonomy, secretary treasurer, dispatcher, President gets informed
7b: targeted: senior citizens and special needs people
comments:
THEY HAVE NO VOLUNTEERS
- said they don't really have too much funding

8) Taber Volunteer Fire Department

3. Purpose or mission: To serve the community; do fire, rescue, and EMS
4. task: All members get training (basic fire I and II), actual firefighters, high standard, members based on experience as to how respond, monthly training
Org. chart: Chief, Deputy Chief, 3 captains, 2 Lieutenants, rest are firefighters
- fire association is an open department (no board of directors)

7b: targeted to a variety of people in community
8. Time - family makes sacrifice, their time is contributed too; do open houses at the hall, professional businesses, and members of department
9. Methods to attract: Internally by members that exist, invite them down
Incentives: all personal rewards, helping people, know many people being a small town; do it for social value; main is commitment to community

9) Name: Interfaith Food Bank

3. Purpose or mission: To recognize the human dignity of needy people and assist needy people
4. Executive Directory, paid staff and volunteers assigned tasks to complete
9. Methods to attract: people want to come, don't use method to attract
Incentives: not many rewards, t-shirts, coffee and donuts
18. Diane Randell at City of Lethbridge - Community Development
- "Getting Connected: A guide to help when you really need it"
- talked to her secretary and it's being printed right now, but can go to www.socialhousing.ca for the information that's going to be in the pamphlet (click under resources) - Also, get information from Native Transition

10) Lethbridge HIV Connection

3. mission: through support, education and advocacy, Lethbridge HIV connection facilitates compassionate and effective community responses to HIV and Hepatitis C
4. task: the executive director is responsible for the program planning and implementation.
7b: target group: those who are already infected or are affected, we also target groups at risk, young people on the streets, aboriginals
9. attract: word of mouth, contacting friends of the infected, advertise at the college/university, try to approach practicum students
retention: volunteers don't pay at the conference, volunteer appreciation events

11) South County Treatment Centre

3. mission: to provide addictions treatment to people experiencing additions to alcohol, drugs and gambling.

4. task: we have different departments (i.e. in charge of clinical), we have positions for people, but there is quite a bit of autonomy for staff to make decisions when the executive director is not in the office.
9. attract: current members go out and attract volunteers, through volunteer lethbridge
retention: AGM, involvement, social gathering for them, plaques

12) Birthright
3. mission: we are here to help young women explore their choices. It is the right to every woman to give birth and the right to every child to be born.
4. Task: our volunteers deal with the calls (they mostly have autonomy to deal and answer work related questions, but if not sometimes have to go to the executive director).
6. friendship is a very important service that our organization provides because we give them hope that they are not alone and help them to make an informed decision.
9. Attract: go through church organizations, our displays are good as a source of attraction, contacting people that we know
retention: autonomy in their position as a volunteer, $15 grocery raffle when they help out at the bingos, a party that is subsidized, training

13) Rehabilitation Society
3. mission: to have a positive impact in delivering services to people who live with a disability.
4. task: team based and we give autonomy to everyone
6. adaptation is the most important service we provide because we want to help people achieve their dreams
comments: we don't really have a big volunteer program, but we plan to in the future

14) Scouts Canada
3. mission: is to contribute to education of young people on the value system-based scout promise and law to help build a better community where people are self-fulfilled as individuals and to plan a constructive role in society
4. task: individual projects working towards a common goal. Individual scout leaders plan a year in advance, but given freedom as long as promoting mission and that they follow risk management rules
7b: targeted to: families, young individuals from the ages of 5-26
9. attract: we develop a job description and then show people and get them to recommend someone they know. It is really effective.
Retention: awards system – long service award, 50 year award, awards for outstanding service; thanking them, training courses paid for them (i.e. coaching)
11b: basis for evaluation: it is decided Canada-wide

15) Nordbridge Senior Citizens Association
3. mission: the provisions of educational, recreational, social, and support services and programs to Senior Citizens from throughout the City of Lethbridge, with a particular focus on fostering independence, self worth, and a sense of community pride amongst seniors of North Lethbridge.
4. task: we have job descriptions for both staff and volunteers. They can seek answers from the director or from the board of directors. The volunteers are given quite a bit of autonomy (i.e. they decide the destination for the travel group on their own).
9. attract: advertisements in monthly newsletter advertising the current opportunities in all volunteer positions.

Retention: social benefits, they know they are helping out their community, plaques, dinners, there are government run programs that recognize volunteers (so, we nominate our people).

16) Womanspace Resource Centre
3. mission: we are a woman's resource centre in operation to assist women with anything we can (resources, referrals, education). For example, by organizing International Woman's Day, by linking women up with people in the community.
4. task: everyone has autonomy to perform tasks. We mostly have contract employees so how and when they complete the work is up to them.
7b: target to families (usually single mother and family)
9. attract: volunteer lethbridge
retention: try to treat them well, show our appreciation
11b: basis for evaluation: the coordinator decides
14b: we are restricted to what we can receive by way of funding because we do not have a charitable number.
18. comment I have is that poverty is the biggest factor for health care

17) Native Women's Transition Home Society
3. mission: to assist single native women with or without children to adjust to an urban lifestyle
4. task: each teacher develops own workplan and it is usually completed 3 months ahead of time (they do this on their own). The executive director steps in for things like financial problems, the board steps in for things like policy issues.
7b: target: aboriginal women and their families
9. attract: volunteer lethbridge, they may have once come through our programs, practicum students (UCC, U of L)
retention: recognize through volunteer lethbridge, we do a nice send off for our volunteers (i.e. write a letter of reference), gifts
11b: basis for evaluation: we let the client decide

18) Touch of Taber
3. mission: making Taber a pleasant welcoming because if people feel welcome in a short period of time it will change the way they view Taber forever
4. task – well there are only 2 of us (volunteers) and so we share the responsibilities equally
7b: target: families
9. attract: we would like to see another volunteer, but you just can't though anyone into this position, you exemplify what Taber is by how you conduct your organization and the welcoming (service)
11b: we make our own evaluation criteria

19) Canadian Red Cross Society
3. mission: service the most vulnerable
4. task: for the community initiative aspect of the organization – it can be decided locally, but for the mandated areas (water safety, disaster, etc) it is decided at a national/international level
7b: target individuals
9. attract: testimonials, put a case in the paper
retention: keep track of all their hours and then reward them at awards night, training, volunteer of the month, support for our volunteers (i.e. we sent people to N.Y. after Sept 11 and then a few of them required counseling after that and we provided that to them)
11b: local office decides their own evaluation criteria
14. Fundraising in the form of gaming is the biggest source of funding. We get most of our money from Casinos that we run.

20)Taber Special Needs Society
3. mission: to help adults with developmental disabilities with their living and working
4. task: it depends, but mostly the executive director delegates
7b: target to the individuals and families
9. they don't have any volunteers

21) Canadian Paraplegic Association
3. mission: assists persons with spinal chord injuries and other injuries to achieve independence, self-reliance, and full community participation
4. task: there is only 1 person in the office, so all task comes in to that person
7b: targeted to individuals, families, and communities
9. attract: Word of mouth, recruit from client base (peer volunteers), volunteer lethbridge
retention: celebrate volunteer week
11b: evaluation basis is set up by way of quality assurance that is Alberta wide

22) St John Ambulance
3. mission: to enable Canadians to improve their numbers and quality of life by providing training and community service
4. task: area manager oversees the task accomplishment and then delegates to the 3 paid staff
7b: target audience: don't have a specific target audience – general public, schools and occupational health
9. attract: volunteer lethbridge, through promotion at our first aid courses, through all schools in Lethbridge, job-shadowing program
retention: thank you notes, discounts on courses for them, bbq once a year, bursaries or scholarships, plaques
11b: who decides evaluation: government standards workplan and task list

23) Safety City Society of Lethbridge
3. mission: reduce the number and severity of child injuries through safety education
4. task: team effort
7b: targeted to children
9. attract: word of mouth, personal contacts, somebody they know will get someone else to join
retention: value from the work, recognition of the work they do, they stay because they believe in the cause

24) Schizophrenic Society of Lethbridge
3. mission: to alleviate the suffering caused by schizophrenia and other related mental illnesses
4. task: mainly the office manager assigns tasks
7b: targeted to families and individuals
9. attract: word of mouth, LCC career fair, volunteer lethbridge, TV and radio spots
retention: volunteer recognition every year (take the volunteers out to a barn dance), words of praise, certificates
11b: every year, business planning meeting with the board to decide evaluation basis

25) Fibromyalgia and Chronic Fatigue Association
3. mission: to invite people with these syndromes to come together to discuss things we have all tried for discomfort
4. task: efforts are done together, always come together as a group on things
6. they mainly provide support because that is why they started the group in the first place
7b: target to communities and families
9. attract: volunteer lethbridge

retention: honorarium
11. number of clients served because every person that gets better is a basis for evaluating. There is no real formal basis for evaluation set up.
comments: disability recognition needs to be known. We don't have a set income, not really getting any source of income. We would like to see some accessibility to funding for our low-income clients would be nice

26) The Arthritis Society
3. mission: to improve the quality of life for affected by arthritis and to support proactive efforts directed toward prevention, diagnosis, treatment and a cure for arthritis
4. task: team effort (Southern Region manager and part-time staff member), but they do divide up own daily duties
6b: education is the most important service that they provide because arthritis needs to be communicated and understood that it is not just older people that become inflicted with it
7b: target the southern Alberta community (all ages)
9. Attract: advertise on the web site, at volunteer lethbridge, connections with college and university, advertise at the senior's centres
Retention: recognition – thank you notes are sent out, sometimes order lunch for them, given key chains
11b: who decides the basis for evaluation: board of directors

27) CORD
3. mission: to provide information and support to over 6000 Canadians with rare disorders
4. task accomplishment: we give autonomy to the one paid staff. If there is something that she can't handle, then she will go to the president.
6b: education is the primary service that our organization provides. We find that even medical professionals consult us on education. We also feel it is important to educate caregivers as well
7b: target families and individuals affected by a rare disorder
9. attract: accessed some of our volunteers through volunteer lethbridge and by W.O.M
retention: offer opportunities for training, recognize them with a wine and cheese, and they come because they want to and because of that, they stay
11b: evaluation criteria: decided by board of dir

28) VON Alberta South
3. mission: VON, a charity, guided by the principles of primary health care, works in partnership with Canadians for a healthier society through: leadership in community-based care, delivery of innovative, comprehensive health and social services, influence in the development of health and social policy
4. task: work as a team (every morning, they meet in a meeting and discuss the clients coming for that day as well as daily tasks), they perform job rotation (i.e. one day recreation therapists will do the games and lunch clean up and another day it will be the program aid's responsibility), eventhough the program coordinator (an RN) overlooks the Lethbridge office, we are all trained to do each other's job, this is helpful when there is staff on holidays and to ensure variety.
9. attract: advertising (TV, internet, and newspaper)
volunteer lethbridge, brochures, w.o.m.
retention: orient and train, volunteer appreciation, career direction for the volunteers, offer them referrals (i.e. we had a U of L student volunteer and we provided her with a reference letter), reciprocal feelings (they do it for themselves).
18. comments: starting to worry about volunteers because their average age of their volunteers are between 65-80. What is going to happen when they get too old to volunteer?

29) Lioness Club of Taber
3. mission; to be of service to the community
4. task: we have a meeting everytime we want to discuss workload. We decide collectively. However, we do have set committees for some issues
6b; community development is the primary type of service our organization provides because we really want to just help out as much as possible in any way we can
7b: target: community of Taber
9.attract: word of mouth, bring a friend night at Lioness club nights
retention: supper meetings, perfect attendance pins, social aspect as a reward.
11b: it is our organization as whole who decides together the evaluation criteria

30) Lethbridge Society for Meals on Wheels
3. mission: to provide hot noon day meals to people who are ill, old or mentally ill
4. task accomplishment: two paid coordinators that job share and then delegate to the volunteers from there
9. attract: media, newsletter, word of mouth
retention: once a year, a volunteer recognition day

31) Taber Food Bank Society
3. Mission: to help the needy
4. Task Accomplishment: goes through office manager, she puts to the volunteers to make hampers, stock shelves, and drive to pick up food in the community.
7b: the services are targeted to the community
8b: Time is the primary source of contributions by volunteers because they help to make the organization survive
9. Attract volunteers: churches send them over and we ask churches for them.
11b: she decides the basis for evaluation criteria

32) Suicide Crisis Line
1b: Social Welfare is our number one choice because their objective is suicide prevention
3. Mission: The Samaritan volunteers will be available at all times to listen to those who are lonely, depressed, suicidal or in crisis. Samaritans provide confidential non-judgmental support, the Samaritans will be responsible to the needs of the community and the well-being of the individual.
4. Task accomplishment: work all comes in from the 24 hour crisis line
8. group targeted to: individuals
9. Attract volunteers: use tv, volunteer centre, distribution of print materials and displays
Retention: volunteer appreciation strategies
11b: basis for evaluation: Board of directors decides

33) Canadian Cancer Society
3. mission: the irradiation of cancer and the enhancement of the quality of life of people living with cancer
4.Task Accomplishment: annual work plan in conjunction with the budgetary process. Passed on to each employee or volunteer. Looks at who is responsible for each category
7b: targeted to: no answer
8b: Reason for the primary volunteer contribution: time – because the cancer society would not function without the time volunteers give
9. Attract: media, volunteer lethbridge, volunteers often come to them as they have been touched by cancer, telerecruiters

Reward: ongoing recognition is policy whereby they thank volunteers, annual recognition event for all volunteers, rewards program, amount of time and specific criteria
11b: the decisions for evaluation criteria are decided divisionally and the work cooperatively

34) Boys and Girls Club of Lethbridge
3. mission: to work with families and adults in offering children and youth to develop skills, knowledge and values they seek to become fulfilled individuals
4. task: organized through program coordinator and assistant coordinator
7b: targeted to: no answer
8b: Primary source of volunteer contribution: time and expertise because it becomes a very good networking and resourcing opportunity
9. Attract: no recruitment, they come to the club, recruit through college and university
Retention: possible full time employment to follow
11b: basis for evaluation: the executive director, Jeff, decides

35) Alzheimer Society
3. mission: we exist to improve the quality of life and comforts of individuals with Alzheimer disease, to educate the public and support caregivers and to promote research in Alzheimer disease
4. task: work together with board members on larger tasks. The office coordinator continues on with the rest of the daily tasks as in meeting with clients everyday. She is the only paid staff, so basically does all the tasks herself.
7b: targeted to families and seniors, i.e. run an ad in the senior paper
9. attract: try to recruit people who are interested, don't really have a method
retention: volunteer appreciation events, thank you notes
11b: board of directors set the evaluation criteria
18. definitely interested in this report

36) Southern Alberta Epilepsy Association
3. mission: strives to promote the concept that epilepsy does not decide an individual's life choices, prospects and destiny and to reduce the misunderstanding associated with epilepsy.
6b: education is very important type of service because it is part of their mission
7b: targeted to schools, day cares, doctors' offices and pharmacies
9. attract: advertise and the university and college, at volunteer lethbridge, by word of mouth, run ads in the paper
retention: 2 different recognition nights (sometimes with certificates)
11b: we evaluate our organization's performance by the number of clients served, we would like to base it on population statistics, but unfortunately, no one really knows how many people in this area or in Canada who have epilepsy

37) The United Way
3. mission: to build a better community by organizing the capacity of others to care for one another.
4. task: help others – facilitate workplace campaigns; work with business to participate; solicit support from the community.
6b: workplace campaign and payroll deduction
7b: printed material in the workplace and media.
9. recognition: "atta-boys"; it is a labour of love; have recognition program but many people don't want anything.
11b: basis for evaluation: fundraising and distribution of funds.

14b: donations through workplace campaign

38) Kidney Foundation
3. mission: the Kidney Foundation is a national volunteer organization dedicated to improve the health and quality of life of people who have kidney disorders.
4. task: have two streams – one deals with programs, the other deal with fundraising.
6b: new program to promote organ donation.
7b: fundraising through March door-to-door campaign.
8b: primary contribution of volunteers is fundraising.
11b: basis for evaluation: meeting fundraising targets.

39) Lions Club of Taber
3. mission: to be of service to the community.
4. task: We usually have a meeting and at the meeting we all decide. If we can not, then, the president decides. To simplify matters, we usually assign chairpersons to oversee each project. It works better that way.
6. why: because they really just want to help out their community as much as possible
7b: target: the community (Taber)
9. attract: word of mouth, someone brings a friend to the supper meetings
reward: perfect attendance pins

40) Barons-Eureka Family Support Services
3. mission: empowering people in a changing world
4. task: each area coordinator decides and then they execute from there
7b: target: communities
9. attract: coordinator does this, also if a parent participates in a course they are offering, a lot of the time, they decide to volunteer after the fact
retention: small honorarium
11. evaluation: we haven't come up with an evaluation format yet, but we are planning to

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From Discovery to Recovery and Beyond: The Voluntary Health Sector's Response to Breast Cancer

Report for Health Canada

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January 25, 2002

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From Discovery to Recovery and Beyond: The Voluntary Health Sector's Response to Breast Cancer

Summary

The purpose of this research report is two-fold: to provide a scan of the voluntary health sector (VHS) organizations in and around Toronto that deal with breast cancer, and offer a framework to assess the impact of these VHS organizations.

We find that VHS organizations related to breast cancer have manifold goals; they range from eradicating breast cancer to enhancing quality of life of breast cancer patients and their families. At the macro level, they have been successful in raising the disease's profile in society, and have brought about important changes in government spending for breast cancer research and assisted in putting together screening and other programs related to breast cancer. At the micro level, they help breast cancer patients and their families by providing various forms of assistance, information, counselling, and support groups.

To understand the micro level effects we investigate how women with breast cancer choose to interact with the VHS organizations. We surveyed women survivors of breast cancer in the Greater Toronto Area and asked them about their interactions with VHS organizations. Through the use of a fictional character Mary we offer a narrative of a woman's experience with breast cancer and the contacts made with VHS organizations. We record Mary's story from discovery to recovery and beyond. We analyze our data on the role VHS organizations play in the lives of women with breast cancer.

Using the data gathered from our survey and other methods we provide a comprehensive listing of VHS organizations in the Toronto area in the Appendix. The organizations range from small and local support groups to large national organizations, are heterogeneous in nature and pursue very diverse goals. We analyze this diversity to understand the dimensions along which VHS organizations make an impact on breast cancer.

On one hand the diversity of VHS organizations gives this sector its strength. On the other hand, this diversity makes it difficult to measure their aggregate impact. Due to this difficulty we are able to arrive at four *proxy* measures of impact. The four measures include the supply of the services provided by VHS organizations and their distribution by regions, the demand for the services across regions, the impact on incidence, morbidity and mortality across regions, VHS spending as compared with government spending and the impact government spending may have on VHS organizations' ability to raise private resources.

Due to the limitations of the scope of this report, the framework of impact assessment is limited to these four broad areas. We have not fully fleshed out the details involved in obtaining data for the four measures but have provided the initial steps. Only when the flesh is put on the bones of this framework will we know what data is necessary, what is

available, and what can be done at what cost. The framework is sufficiently generic and it can be adapted to other diseases with minor modifications. Suggestions for further research are given in the Conclusion.

Section 1: Introduction

Breast cancer is not a new disease; cases of breast cancer have been documented in early Egyptian times. For centuries, the medical profession has tried to find ways of alleviating the pain and suffering caused by breast cancer and to increase survival rates. Over the years many different treatments for breast cancer have been tried; they range from mastectomies (first performed in Canada in the 1700s) to the current practice of mammography, lumpectomy, radiation, chemotherapy, hormone therapy, monoclonal antibody therapy, genetic counselling, and prophylactic mastectomies.

Given that in Canada alone over one in nine women will be diagnosed with breast cancer and many will die,[1] it is no surprise that breast cancer has become one of the most serious health concerns facing all women. Today millions of women are either living with breast cancer or have a close relative who is. What makes this scenario even worse is that the cause of breast cancer is not known and therefore cannot be prevented.

Although breast cancer is not a new disease, what is relatively new is the response of the non-medical profession in becoming active in promoting and advocating for its prevention and cure. In particular, many voluntary sector organizations and individual volunteers have targeted the prevention, treatment, and cure of breast cancer as the focus of their efforts and funds. They do this through a gamut of actions, including raising public awareness, organizing support groups, counselling, disseminating information, advocating for change in policies, and research. At the macro level, they have been successful in raising the disease's profile in society, and have brought about important changes in the ways government and other organizations expend public money for breast cancer research and in assisting women with breast cancer and their families. At the micro level they have helped hundreds of survivors with their emotional and physical needs in a variety of ways ranging from providing information and forming support groups to assisting with hair loss and physical changes resulting from treatment.

The organizations that are of interest in this study are a subset of those organizations that are designated 'charitable' organizations by Revenue Canada.[2] The charitable, (or what is often referred to as the nonprofit) sector consists of a variety of organizations, of which 'health organizations'[3] constitute 5% of the total number of organizations and received

[1] Canadian Cancer Statistics 1997. National Cancer Institute of Canada, Toronto, Canada 1997
[2] Revenue Canada designates many voluntary sector organizations as Charitable Organizations. These include organizations that are formed for 'charitable' purposes and include many not-for-profit health, educational and research organizations. They are barred from disbursing surplus revenues as profits and receive tax exemptions. Donations to these organizations are generally tax deductible to their donors.
[3] Health organizations include organizations dealing with a variety of issues related to health including research and education, but exclude hospitals and universities.

8.8% of total revenues in Ontario in 1997. The revenues came from government grants and payments (58%), earned income (23%) and private giving (19%) (Hall and Macpherson, 1997).

It is common practice to refer to this group of organizations as the voluntary health sector (VHS) organizations, as we do in this report. Of interest in this study is the subset of VHS organizations that deal with various aspects of breast cancer. We exclude in our study hospitals that are publicly funded, despite the fact that many rely on the use of volunteers and have foundations that accept donations and are registered charitable organizations. However, we will include in our scan specific breast cancer diagnostic and treatment facilities that are located *within* hospitals and may often be funded through the hospital foundations and generally use some volunteer labour.

In this report we provide a scan of the various VHS organizations involved in all issues related to breast cancer in the Toronto region. They range from large national organizations to small grassroots groups, self-help groups and volunteers. In doing this scan, we hope to lay out the initial steps for understanding the contribution of the VHS in the efforts to: support women with breast cancer and their families; find a cure; promote prevention; and, advocate on behalf of victims and survivors of breast cancer.

Section 2 of this report will look at the resources available to women who discover they have breast cancer. With the help of a fictional case, we follow the progress of one breast cancer survivor from the discovery stage to the recovery stage and further. This will form the conceptual framework that aids in the understanding of the role VHS organizations play in the lives of women with breast cancer.

The appendix to this paper includes an inventory of VHS organizations dealing with breast cancer and located in and around the Greater Toronto Area, the region of our study. These include national, provincial and local VHS organizations that are accessible in this region or play an active role in the region. We draw information from our interviews of survivors, some key personnel in the VHS involved with breast cancer, and other conventional sources such as electronic searches on the Internet, telephone directories, and word of mouth. Not all organizations in this section have a *direct* role to play with women who have breast cancer; some organizations are involved in advocacy at the policy level or in research. Although in this report we do not specify the details of the role played by each one, we will indicate the mission and role of the organization where possible and provide contact information such as addresses, phone numbers and Web sites. We use information available on the mission and goals of these organizations in arriving at the key dimensions on which we will examine impact in the next section.

In Section 3 of this paper we examine the question of what constitutes the micro and macro levels of impact VHS organizations make on breast cancer, and how to measure impact. We discuss the literature on assessing the effectiveness and impact of nonprofit organizations. Given the difficulties in assessing impact across a heterogeneous group of organizations and limitations of this study, we propose a relatively simple but efficient framework that will enable researchers to assess the aggregate impact of the VHS

organizations on breast cancer at the micro and macro level. In Section 4, we make some concluding comments and raise questions for further research.

Given the nature of the research undertaken, we rely on a theoretical approach that is not limited to a single discipline. We begin with a social-science based approach to qualitative analysis using grounded theory to interpret our results from the survey of breast cancer survivors. The question we focus on is how women with breast cancer rely on VHS organizations for information support or other needs during the period of discovery, treatment and recovery. We use a snowball technique for sample selection in surveying women with breast cancer, and determine the size of the sample based on saturation of information regarding VHS organizations. We do a content analysis of the mission statements (or equivalents) of VHS organizations to determine the dimensions for impact. Using an economic standpoint, we suggest the framework for impact assessment; in particular, we categorize impact from a perspective of the supply and demand for services of VHS organizations, and crowd-out effects of increasing or decreasing government support of VHS organizations.

Section 2: From Discovery to Recovery—What is available to Mary?

What are the resources available to a woman who discovers that she has breast cancer? To answer this question, we survey 15 women and gather information on their experiences as they move from the discovery stage to the recovery stage and further. As a conceptual framework, we take a fictional individual, whom we name Mary, to provide an insight into the role VHS organizations play in a woman's life as she confronts breast cancer. We narrate Mary's experiences as she moves through various stages in her life after being diagnosed with breast cancer.

2.1 Methods

Mary is a fictional character. She represents a composite of 15 women who were interviewed specifically for this research. Her story is made from various parts of stories that actually happened (albeit to many different women). The women chosen for the interview were those who reached out for treatment and recovery to organizations in the Greater Toronto Area. Some of them lived in the City of Toronto and others in the suburbs of Toronto. However, most of the women we interviewed were treated medically in Toronto hospitals and reached out to voluntary sector organizations in and around the Greater Toronto Area. Thus, the city and suburbs of Toronto provide this research with its spatial boundaries, and are the main repository of voluntary sector organizations reported in this study.

In many cases, the women in our sample were approached by VHS organizations as part of the organization's outreach program. However, some had volunteered with VHS organizations prior to their experience with breast cancer. Most of them had picked up information regarding breast cancer from the dissemination of materials put out by VHS organizations. The organizations that our fictional character contacts *are real and do*

exist; a list with limited details on these organizations is included in the appendix to this paper.

The initial contacts for our interviewees were made through the Canadian Breast Cancer Foundation (CBCF). We relied on a snowball technique, getting names of women survivors through word of mouth and from connections with survivors who volunteered in a variety of voluntary sector organizations. Our own personal networks provided additional names.

As we do not try to represent the story of a 'typical' survivor, we were not interested in undertaking the usual considerations in finding interviewees from whose stories we could generalize to the population of survivors. Our aim was to interview survivors whose reach to voluntary sector organizations would cover the breadth of VHS organizations available in the region of our study. For this reason we interviewed women from different socioeconomic and ethnic backgrounds to ensure we would uncover voluntary sector organizations that cater to different types of survivors. Furthermore, we interviewed women who are at different stages in the road from 'discovery to recovery' to ensure that newer and current VHS organizations would be covered.

As the interviews progressed, we noted an increasing overlap of organizations in our list and in those being offered by the interviewees. We continued our interviews until no new organizations were mentioned and we had reached saturation. In the last two interviews, we picked up no new organizations not uncovered by the previous interviewees or our own search.

Confidentiality parameters were provided and all the women read and signed the consent form provided. Many of the women eschewed the caveat of confidentiality offered to them and wished to be identified with their stories. However, in this research we had to decline their offer, because no one story gave us the full map of the reach of VHS organizations that the composite story provides. Their stories, nevertheless, were powerful and inspired us at all stages in the research; we were impressed with the impact VHS organizations had in their lives and how they chose to continue their involvement with VHS organizations even after recovery.

2.2 Sample Characteristics

Fifteen women were interviewed for this study. They ranged in ages from 46 to 63, with an average age of 54. Seven women had discovered their breast cancer through routine mammograms. Six women had found their breast cancer through self-examinations. Only two women had discovered their breast cancers at routine physical examinations by their general physicians. The time from discovery to recovery and beyond for all these women ranges from one year to 19 years.

All but two survivors had their initial surgical intervention at hospitals in Toronto, and two were treated in Richmond Hill, a suburb of Toronto. All but one survivor underwent either radiation or chemotherapy at two Toronto locations: Princess Margaret Hospital or Women's College Hospital.

Several survivors in our sample had significant and protracted interactions with voluntary organizations. In many cases survivors volunteered at VHS organizations related to breast cancer in their recovery stage. Several took leadership roles, although in one case this had happened prior to the onset of the disease. We had a few cases where survivors shunned all interaction with VHS organizations and only dealt minimally with VHS organizations at the venues where they underwent treatment. Two relied heavily on Internet sources for support and information originating within and outside Canada.

While the focus of the study is formal VHS organizations, our sample of survivors, in the majority, relied heavily on the informal networks of friends and family for support and information. Many informal ties through, for example, places of worship, book clubs, neighbourhoods, car pools and volunteers in hospitals offered invaluable assistance. It did not seem that this assistance was a substitute for the kind of support available through VHS organizations;[4] nevertheless, it remains an important and natural resource for nearly all survivors on their road to recovery and cannot be underestimated. The scope of our research does not allow us to account for the informal systems that nearly all women in our sample relied on, albeit for different levels of support.

2.3 Mary's Story

I had read about self-examinations in my local newspaper and had been doing them monthly for almost a year.[5] In January I discovered a lump in my breast. I tried to ignore it, but a nagging voice told me to do something. Later in the week I phoned my general physician, and the secretary gave me an appointment for early the following week. The thought of breast cancer did not leave me after securing the appointment. However, I decided not to cause any distress to my husband or children, as I had no idea what the 'lump' was going to be. Several of my friends had benign lumps, and I hoped that mine would also be benign.

Instead of speaking to anyone, I checked out the Web site www.cbcf.org that was listed in a magazine article I had read that month. I found information on various aspects of breast cancer, although some of it was too premature for me. Later on, I went back to that Web site frequently for information and support.

At my appointment, my physician advised me that there was a cause for concern, but not to worry until we had more definitive information. She reminded me that often breast

[4] Support from informal networks can substitute for some but not all of the different types of support given by VHS organizations such as: up-to-date information, counseling by trained staff or volunteers, and the camaraderie developed in group sessions or through participating in events such as dragon boat racing.
5 See the appendix of this paper for more information on the organizations mentioned in this section.

lumps are benign, but it would need a mammogram and ultrasound to rule this out. She gave me the phone numbers and a note to take with me when I went for the mammogram and ultrasound. The mammogram showed that the lump I had was suspicious. The physician informed me that there was a very high likelihood that it was malignant and made arrangements for me to undergo surgery. I was unprepared and in shock. Only later when I recovered from the shock of knowing I had breast cancer was I able to discuss the various options with my physician and surgeon.

I underwent a lumpectomy in March and node removal. At this time the Canadian Cancer Society(CCS) helped in providing a caregiver for my young daughter. As some of my nodes were involved, I would need chemotherapy and radiation treatment. Suddenly I wanted more information and although I got some information from my doctor, it did not seem like enough. I felt vulnerable and very depressed. At this time there was a breast cancer survivor who came and talked with me about what she had been through and what I should expect. I found this very useful and supportive. Despite the family and friends who supported me through this illness, the support of a survivor was essential to me at this time. She had been there and lived to tell the tale. I am not sure whether she was a hospital volunteer or came from another organization.

During the early days of my treatment, I was contacted by a volunteer from the Reach to Recovery program and attended two support group sessions. Volunteers from the Ontario division of the Canadian Cancer Society helped in providing transportation when I needed to go for my treatments, and I am grateful for this assistance.

I then started more actively to research the disease through a variety of Web sites, linkages through the original Web site such as Canadian Breast Cancer Research Initiative and Canadian Health Network. On these links and other Web sites I found out about the variety of kinds of treatments, and what breast cancer can mean in terms of life changes. This browsing of Web sites helped me to stay focussed on my illness without getting depressed.

In May I underwent chemotherapy for six months and was offered support groups and information videos by the medical staff. At this time I declined all this support. During my radiation treatment I was referred to the "Look Good, Feel Better" program. This was a wonderful program. I attended a workshop and learned how to look better, including new ways of putting on makeup and how to choose wigs. I received not only cosmetics but left with a renewed sense of self-confidence, control and hope. I also started to attend my local breast cancer support group. These sessions allowed me to share my concerns with other women and listen to theirs. A level of camaraderie developed which nurtured me and helped me deal with the anger and helplessness I had felt since I had discovered my breast cancer.

When I felt better, I was determined to do some volunteering for breast cancer research. I have two daughters and felt the need to do something. I also wanted to volunteer as a way of giving back for the support I received from many VHS organizations along the way. The first opportunity came at the Run for the Cure. This annual event raises money

for breast cancer research. I volunteered at the event and found it extremely rewarding. Many of my friends and family took part. Later that month, I approached the Willow and offered to be a volunteer visiting other women diagnosed with breast cancer. Two years later, I joined the Ontario chapter of the Canadian Breast Cancer Foundation and served on their education committee. At this time I heard of the dragon boat race. I joined other survivors and took part in the dragon boat race.[6] *This was one of the activities I enjoyed very much as it helped to build my physical strength and gave me a goal to work towards – a great healing process for me emotionally!*

My work with other women in breast cancer support groups is very valuable to me. It reminds me of the time I was experiencing great distress. It is a rewarding experience to be able to help other women during their times of distress. My primary interest in volunteering with the larger organizations was to raise the profile of breast cancer in the general public and help fundraise. This helped me as a survivor to overcome the feelings of being out of control and being alone in my fight with breast cancer. Although many of these VHS organizations exist to fund future research and offer ongoing support of breast cancer victims during their times of stress and need, they also provide an outlet for women to work together in the fight against breast cancer. By volunteering with these organizations, I felt I had really confronted my disease head-on and taken positive steps in my journey to recovery.

2.4 Analysis

Mary's story identifies several interactions of VHS organizations along her road to recovery. Clearly the VHS organizations were instrumental at two levels at the initial stages in providing information and support for her physical and psychological well-being.

Like most women in our sample, Mary's reliance on the VHS organizations comes only after surgery, with the brief exception of the initial Internet search.

Mary is unusual in the number of contacts she made with VHS organizations; the average number of contacts made by our sample is 2.2 during treatment. Since this is not a representative sample, we cannot generalize to the population of survivors. Given our method of eliciting our sample, this number may be high as we relied on VHS organizations to provide us the initial names.

Women in our sample, after their treatment stage, volunteered their time to an average of two VHS organizations related to breast cancer. This ranges from fundraising by walking at the CBCF Run for the Cure to assuming leadership roles at large breast cancer VHS organizations. Again, this may not reflect the trend for the population. But one thing we learned was that such type of volunteering, for many of the women, enhanced their own sense of being in control of the disease by making a contribution to the fight against

[6] See "How to Ride the Dragon" by Michelle Tocher for an insight into the effects of dragon boat racing in the struggle to cope with breast cancer.

breast cancer. Many women felt it was a way to give back the support they had received from other survivors acting in volunteer positions.

Unusual in our findings is that nearly all women only approached VHS organizations after surgery. It would be reasonable to expect that women who received a breast cancer diagnosis would have reached out for information and support prior to making their decision on the nature of surgical (or non-surgical) intervention. With the exception of one woman who called the CCS prior to surgery, none of the women had any contact with VHS organizations until after surgery and usually during only chemotherapy or radiation therapy sessions. At this time they were approached by volunteers involved in outreach programs or joined support groups with which they later had ongoing relationships.

During the times of intense stress, the time between diagnosis and surgery, it seemed unusual that there was no VHS organization involvement. There was no outreach from VHS organizations, nor was there any effort on the part of women newly diagnosed with breast cancer to take advantage of the information and support available. At the time when important decisions are being made and the terms of reference in dealing with the disease are negotiated by each individual and her family, the only contacts seem to be the physician and surgeon. One caveat to this finding was the availability of information on the Web sites of many VHS organizations that were accessed by a couple of women in our sample. However, one woman remarked that the information available "was too much and too scary" at that early stage.

Section 3: Framework for Analyzing the Impact of VHS Organizations

VHS organizations' impact occurs at two distinct levels: the impact on women diagnosed with breast cancer and their families as well as women seeking information, prevention, and screening. We refer to this as the micro level impact. The second impact is at the macro level; this includes research on prevention, screening, treatment and cure of breast cancer and advocacy in the policy arena. In both cases, VHS organizations play a major role and therefore have a direct and indirect impact on women with breast cancer and all other women who may be potential victims of breast cancer.

It is important to measure this impact so that resources can be directed to those efforts where the impact is optimal. Government, the major funding source for VHS organizations, as well as private donors, need to know that resources diverted to VHS organizations (from other competing needs) are indeed making a positive impact at either the micro or macro level on breast cancer.

How do we measure this impact? As with most social science questions, it is not possible to do so without great costs that include well conducted survey research. Furthermore, as the scan of VHS organizations in the appendix to this paper reveals a vast heterogeneity in the sector, it becomes increasingly difficult to aggregate the impact of organizations in

the sector. How does one find an aggregate measure of impact when organizations' goals range from providing group therapy sessions to advocating for policy changes?
It is well recognized in the literature that impact measurement is difficult in the realm of nonprofit organizations, especially in defining one measure that is meaningful over the sector as a whole (Herman 1999). Very often goals of nonprofits are not easily measurable as they are often related to psychosocial outcomes and the enhancement of quality of life (Forbes 1998). In the case of VHS organizations related to breast cancer, the question of measuring their impact is difficult on several counts.

Many organizations in our study have multi-pronged goals. To quote one example,

> The Canadian Cancer Society is a national community-based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. Canadian Cancer Society achieves its mission through research, education, patient services and advocacy for healthy public policy. These efforts are supported by volunteers and staff and funds raised in communities across Canada. [7]

This suggests that the impact of the CCS must be judged on the basis of the eradication of breast cancer, and the enhancement of the quality of life of cancer patients. In the first instance, incidence and mortality rates related to breast cancer can help to measure the impact. Nevertheless, it would not be easy to isolate and measure the impact of the CCS. For example, even if the rates of incidence and mortality are decreasing, it would take careful study to establish how much of that decrease was due to the efforts of the CCS, other VHS organizations that share this goal, or environmental factors.

We note there exists a wide range of VHS organizations whose complete or partial focus is breast cancer. (See the appendix to this paper for details). Their efforts include some combination of prevention, screening, treatment, enhancement of quality of life, outreach, support, education, information dissemination, research, and community capacity-building. Their aim is to aid all women who may be susceptible to breast cancer, those who are living with it and their families and friends. Other organizations are involved with larger issues of networking, dissemination, research and advocacy. Many are large, well-funded organizations and some are small grassroots organizations without any significant budgets. The question pertinent to our research in this section is how to assess their impact on 'breast cancer' at the macro and micro levels.

To do this, we analyze the data on the organizations in the appendix and articulate several dimensions that would capture the various undertakings of VHS organizations involved with breast cancer at both micro (patient) level and macro (disease and policy) level. After reviewing the VHS organizations and their stated missions, we did a content analysis to elicit the dimensions along which impact may be assessed. We arrived at eight fairly distinct dimensions, and not all dimensions are relevant for all organizations as they have different missions and goals. The dimensions were chosen by selecting the top eight

[7] http://www.ontario.cancer.ca/Siteboth/English/CCSA7B1C0D0E0F0G0.asp

that appeared with the highest frequency in the mission statements (or equivalent) of the VHS organizations in our inventory. We note that some VHS organizations in our list are only partially focussed on breast cancer amongst other cancers and others are completely focussed on breast cancer.

The dimensions given below are not mutually exclusive. For example, 'dissemination of information' is often linked with 'education and awareness' and may be collapsed into one dimension. Nevertheless, we chose to mention them as separate dimensions as they often appear separately. For example, educating the public at large on the need for self-examination and screening is distinct from providing information on where the support groups or other resources are located. However, depending on the kind of VHS organization being studied, these dimensions can be augmented or collapsed. The dimensions along which impact can be assessed are as follows:

1. Prevention
2. Diagnostic and screening
3. Treatment and therapy
4. Quality of life (Psychosocial support for cancer patient, family and friends)
5. Dissemination of information
6. Education and awareness
7. Research on screening, treatment, prevention and cure
8. Policy advocacy

Assessing impact is difficult for most of these dimensions. For example, how do you measure impact on the quality of life? Qualitative measures would necessitate careful survey techniques with appropriate controls. Concrete measures such as increasing survival rates, or decreasing incidence or mortality rates do not capture the impact on the quality of lives and morbidity. To capture the impact on quality of life, survey methods involving women who have access to VHS support organizations and women without access need to be compared. Clearly the result from Goodwin's (2001) recent study[8] and other literature (Davison, et al. 2000 and Spiegel, et al. 1989) suggest that such impact is not negligible. The literature also suggests methods for evaluating these types of impacts on morbidity and quality of life.[9]

Education and dissemination of information is an important goal of many VHS organizations for a variety of reasons. It is best articulated in the handbook issued by Health Canada entitled *Questions and Answers on Breast Cancer*, a guide on breast cancer care for both women and physicians. The introduction sets the tone by stating that women now have a voice in their treatment:

> If you know what the experts are recommending for your condition, and why they're recommending it, then you'll know what to expect and be

[8] Contrary to popular opinion, support groups do not extend the lives of women with advanced breast cancer. However, women assigned to support groups had greater improvement in psychological symptoms and reported less pain than women in the control group (Goodwin 2001).

[9] See Humphreys & Rappaport (1994) and Riessman, & Carroll (1995) for methodological issues and further references.

> able to make the best personal choices. As an active participant in your own care, you'll know what's going on and you'll be able to ask the right questions.

A study conducted by Gray et al. (1998) has reported on increased need for information by women with breast cancer. Much but not all of the information usually emanates from health care personnel involved with the patient. VHS organizations also play a role in providing information through a variety of ways including published literature, Web sites, support groups and information networks. The value of providing information extends beyond satisfying a simple need for information; it encompasses the many aspects of patient well-being. [10]

Degner et al. (1997) conducted research in Manitoba on informational needs and decisional preferences among women with breast cancer and concluded that 66% of women wanted to either make their treatment decisions on their own or in collaboration with their physicians.[11] These findings certainly suggest the important role of information dissemination in making appropriate decisions and in well-being.

There is little doubt about the impact of availability of information in the lives of women with breast cancer, and the involvement of VHS organizations in disseminating information. But a question remains. How do we measure this impact and aggregate it into other measures of impact for other types of VHS organizations? Similarly, how do we judge the impact or effectiveness of VHS organizations' involvement in policy advocacy or research? These questions are important for policy decisions as funders, government or private, need to know where best to allocate resources for optimal results.

It is interesting to note that assessing impact and/or effectiveness in the nonprofit sector at large has been plagued with controversies and doubts. The scholarly literature abounds with publications lamenting the lack of availability of measures that can work across the sector and even within subsectors. Given the heterogeneity of the kinds of nonprofits in the sector and the variety of goals they pursue, this is not surprising. Recent reviews of the literature suggest that effectiveness studies of nonprofit organizations "are characterized by varying theoretical perspectives and research objectives which make accumulation and integration impossible" (Herman and Renz 1999, p.107).

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[10] Patients receiving information show: greater involvement in treatment decision-making; better preparation for medical procedures; increased satisfaction with treatment choices and interactions with health professionals; improved coping with the stress of diagnosis; decreased levels of anxiety, mood disturbance and distress; and, greater ability to cope during and after treatment. (See Gray, et al 1998 for references.)

[11] This was especially true for younger and well-educated women. Their priorities for information are related to 'the chances of cure,' and 'the spread of their disease.' Understandably, information given by VHS organizations cannot be tailored to individual cases but can give a broad range of options and associated risks and benefits useful in eliciting questions that women can take up with their physicians.

There is sufficient debate in the literature on how to measure impact and effectiveness.[12] One accepted method is goal achievement: a nonprofit's effectiveness can then be measured by noting whether it achieved its goals as there is a lack of other bottom-line measures such as 'profit,' 'return on investment' and 'share prices.' But this begs the questions of how nonprofits see their goals. Are they mission statement goals, or do they represent the current board's goals, or those of the manager? And, are nonprofits sometimes pursuing unwritten goals that may be driven by the funder?

Institutional theorists argue that 'effectiveness' is not an objective reality, but rather a social construction where agents representing the organization convince other stakeholders that the organization is pursuing the 'right objectives' in the 'right way' (Scott 1995). Furthermore, due to the heterogeneity of the sector, and because nonprofits often engage in a social transaction (distinguished from a commercial or political transaction) some scholars agree that it is impossible to find a meaningful measure of effectiveness. In addition, a statement on effectiveness generally implies that the organization under consideration is more or less effective than other organizations or some ideal. Such comparison, although implicit, is not relevant unless a single measure of comparison is available (Herman and Renz 1999).

In this report, due to these difficulties mentioned above and due to the limitations of the scope of the study, we suggest several proxy measures of impact. One measure we suggest is the use of financial and volunteer budgets of the VHS organizations.[13] This is admittedly a rough and ready measure that will not capture all the impacts of VHS organizations on breast cancer along the dimensions mentioned earlier. However, we defend the use of this measure on several grounds.

First, and most important, is that this is an easily accessible figure as compared to the in-depth studies requiring knowledge of the organizations' goals, how they are attained, satisfaction of multiple constituencies, or other models suggested in the literature. The types of VHS organizations involved in the various facets of breast cancer are sufficiently heterogeneous that no model is likely to be relevant for all the organizations in this study. This would make it impossible to aggregate the impact of all the VHS organizations involved (listed in the appendix to this paper). Thus if we are to aggregate the impact of the VHS organizations, a quantifiable measure such as resources is useful and efficient.

Second, we believe the revenues and resources that any VHS organization is able to raise through its supporters (granting bodies, donors, volunteers and clients) reflect some measure of effectiveness and impact. Underlying this assertion is a reasonable assumption that the organizations are able to make an impact that is proportionate to their resources. In addition, the VHS organization has been able to convince supporters that

[12] Scholars writing on effectiveness discuss measuring effectiveness using a variety of models: reaching organizational goals (Herman and Renz 1997, Strasser, et al., 1981); systems resources, internal processes, competing values, legitimacy and fault driven models, (Cameron 1986); multiple constituencies models, (D'Aunno 1992); maximizing, political, constituency, business and paradoxical (Meyer and Gupta 1994); and, constituent satisfaction models (Kushner and Poole 1996).

[13] In Herman and Renz, 1999 on page 123, they suggest the use of size and growth as easily accessible impact indicators.

the service it provides is 'effective' and makes some acceptable level of 'impact' given the environment in which it operates. This relies on the fact that supporters are not likely to give money or time to organizations they believe are ineffective or wasteful (Handy 2000). Finally, a significant portion of the revenues of VHS organizations comes from government sources and therefore it can be argued that this reflects multiple constituencies and satisfies multiple stakeholders concerning the impact of the goals pursued.

The measure of resources (money and time) would include the size of the organization's budget and the number of volunteer hours contributed to the organization in a given period. Many larger VHS organizations fund and support smaller local affiliates as well as independent VHS organizations. To avoid double counting of financial resources at the aggregate level, resources flowing within the VHS organizations will have to be accounted for and duly subtracted from the aggregate budgets.

For those organizations reaching out to women with breast cancer and involved in providing services such as counselling or assisting with transportation, the impact measure is the number of women served. Comparing this on an annual basis with the statistics of women diagnosed with breast cancer would serve to assess the impact of VHS organizations. Another way to view this impact is to measure the number of organizations a woman with breast cancer reaches out to—an average measure of use of VHS organizations by women with breast cancer. In our sample, women averaged two, but our sample is far from being representatives and a more accurate figure is required with a more comprehensive survey across regions. Variation of accessibility by region can be compared to usage to further understand impact.

Furthermore, statistics on the use of VHS organizations and the incidence of breast cancer and morbidity and mortality rates can be developed for various regions and compared. The differential impact of VHS organizations by their distribution (and therefore the differing access available to women) is an important way of assessing the impact of VHS organizations. For example, the lowest breast cancer mortality rates have occurred in the two provinces with the most extensive screening and highest levels of mammography, suggesting an impact of screening facilities.[14]

Longitudinal studies could be made to indicate the growth in VHS organizations. Growth rates would indicate the VHS organizations' responsiveness to constituency needs and expectations. Such growth rates can be compared with the growth rates in the incidence of breast cancer, and the mortality rates from breast cancer, to get a more complete picture of impact.

Finally, since VHS organizations are undertaking activities that would otherwise be borne by the government-financed health care programs, the financial impacts of the VHS need to be evaluated in relation to overall spending in the health sector for breast cancer. Measures on how policies that withdraw support from VHS organizations may affect

[14] Canadian Cancer Statistics 1997. National Cancer Institute of Canada, Toronto, Canada 1997.

private and public spending must be determined to avoid an undue burden on the public purse.

Is it possible to settle on these few proxy measure for the impact of the VHS organizations on breast cancer? In a perfect world, several models suggested in the literature would give us a clearer picture of the impact—goal attainments, program evaluations, outcome indicators, and stakeholder analysis, all of which seem relevant to some subset of organizations in this study.[15] Even if these models could be used for VHS organizations in our study, no one model could be relevant to all organizations. Consider the evaluation differences in measuring effectiveness for local support groups such as Wellspring and the larger national advocacy group, the Canadian Breast Cancer Network. This would lead to an overall difficulty of aggregating the impact of VHS organizations, the question this study set out to measure.

We are thus forced to conclude that to measure *overall impact* of VHS organizations on breast cancer we must rely on a small number of fairly easily measured indicators such as size (revenues and resources), distribution, number of clients served, incidence of disease and mortality. These impacts are divided into the following four categories: supply; demand; regional comparisons on incidence, survival and mortality rates; and, effects of government spending.

Proceeding along the lines of the discussion above, we suggest the following framework for assessing the impact of VHS organizations on breast cancer:

A. Supply

1. Map of the VHS organizations dealing with breast cancer—number, type, size and age—as well as their distribution into regions with differing access. (Regions are defined for the purposes of comparison for #6 and #7.)
2. Monetary and non-monetary resources used by organizations in #1 while pursuing their mission. For organizations with several goals, these resources should reflect only those targeted to breast cancer. These figures are obtained from annual reports and budgets and statistics on volunteer usage (in hours).
3. Take into account flows of revenues within organizations in the VHS to exclude double counting.

B. Demand

4. Compile figures for the number of clients served by the organizations in #1 for the regions under study.
5. Using survey methods, in each region determine the average number of VHS organizations a typical woman with breast cancer uses for her own needs and volunteers with.

[15] See Plantz et al. (1997) and Forbes (1998) for some examples.

C. Comparative data

6. Note the incidence and mortality rates from breast cancer and the distribution of different types of VHS organizations for each of the regions.
7. Determine, using appropriate survey methods, the morbidity among women with breast cancer in regions where there is greater access to support systems offered by VHS organizations and regions where there is a distinct lack of such support.
8. Compare usage and accessibility variations over regions.

D. Impact effects of government spending

9. Determine expenditures made directly and indirectly by government in dealing with the various facets of breast cancer (medical insurance programs, infrastructure expenses, etc.) and assess the relative share of the VHS organizations' contribution to breast cancer.
10. Assess the burden that would be shifted to the government-financed medical system if government funding to the VHS organizations decreased.

The figures in #2 and #3, when aggregated over the VHS organizations in the particular region for a period of time, will begin to assess the impact of the VHS organizations from the supply side on the various facets of breast cancer. The figures in #4 and #5 will indicate the demand for the services provided by service-oriented VHS organizations. Information from #1, #6 and #7 will yield comparative information on the impact of VHS organizations in terms of morbidity, mortality, and survival. But such data, especially on morbidity, will require careful survey analysis like that attempted by Goodwin et al. (2001) into the lives of women with breast cancer in different programs across different regions.

Finally the information from #8 and #9 will yield information on what resources are contributed by the government in the presence of the VHS organizations, and what shortfall might have to be made up for by governments in the absence of VHS organizations. As noted earlier, government input accounts for 58% of revenues of the VHS while 19% of revenues come from private donations. Furthermore, many VHS organizations also benefit from the availability of volunteers. In 1997, for example, 1.3 million Canadians volunteered for a total 108.6 million hours to VHS organizations and 2.3 million Canadians made financial donations for a total of $772 million (Heinz 2001). If government were to substitute the services provided by VHS organizations, it would not necessarily have access to private donations of time and money, thus making similar provision of services more demanding on the public purse.

Clearly not all services may be replicated by the government, but because of their inability to attract private donations, the cost of the services would increase. On the other hand, if government contribution to VHS organizations increased, would there be a

crowding out of private sector money?[16] Such information can be useful to policy makers in determining the consequences of reducing or increasing funding to VHS organizations.

The framework suggested above is limited and uses proxy measures for the impact, particularly in the areas of research and advocacy. However, this is a beginning. We hope that this study will invite further research to measure the impact of VHS organizations as well as to spur the fine-tuning of this framework or develop other more suitable measures of impact.

Section 4: Conclusion

In this report we examined the response of VHS organizations to breast cancer. They are active in promoting research, engaging in advocacy, and disseminating information and raising awareness for the disease at the macro level. At the micro level, they help survivors by providing assistance, information, counselling and support groups all aimed at enhancing quality of life for women with breast cancer and their families.

In section 2, through the use of a composite fictional character, we examined the role VHS organizations play in the life of women who discover they have breast cancer. We followed Mary through her journey from discovery to recovery and beyond. We note her involvement with VHS organizations and thereby confirmed the importance of these organizations in the lives of women with breast cancer and their families.

Our data reveals a finding worth pursuing: the lack of VHS organization involvement during the time between diagnosis and surgery. It seems unusual that there was no VHS organization's involvement at this time of intense stress when women appear to be looking for support and information in reaching their decision on which treatments to adopt.

A comprehensive listing of VHS organizations generated by our survey and other techniques are included in the appendix to this paper. This list shows a variety of organizations and their manifold goals related to breast cancer. They include advocating polices that promote greater research for the eradication and prevention of breast cancer as well as forming coalitions, networks and other systems of infrastructure to promote education, dissemination of information and assistance to women who have breast cancer or are likely to contract the disease. The organizations range from small and local support groups to large national organizations. Using this data we were able to generate a range of dimensions along which impact can be articulated in Section 3.

We noted that there is much debate in the literature on measuring impact and effectiveness of nonprofit voluntary organizations. In our particular case it is further compounded by the fact that the VHS organizations are diverse and hence the impact of

[16] Whether there is a crowding out of private resources with respect to government funding has been much debated in the economic literature. The evidence available to date suggests it is difficult to predict what, if any, the partial effects may be.

their services offered at the micro or macro level (or sometimes both) cannot be easily integrated. Using the dimensions along which impact is meaningful for this diverse set of organizations, we proposed a range of measures to examine the impact in four categories. The four categories proposed examine the supply and demand of the services, comparative information on the impact of VHS organizations in terms of morbidity, mortality, and survival, and finally the impact of VHS spending as compared with government spending.

This framework is the first of its kind in assessing impact of the voluntary sector on a particular health problem. We have not fully fleshed out the details involved in obtaining data for the eight steps outlined; it is beyond the scope of this study due to time and resource constraints. Further research remains to be done—putting flesh on the bones of the framework. This level of detail will reveal what can and cannot be done and at what cost. The framework is sufficiently generic and it can be adapted to other diseases with minor modifications.

To be sure, the framework is limited in one important way—it cannot measure the depth of the impact in the lives of the women nor the effectiveness of advocacy and research undertaken except by using proxy measures of size and resources. Furthermore, it is also unable to account for the tremendous support and information available in informal networks through friends, places of worship, etc. Nevertheless, it is a framework that we hope will initiate an ongoing discussion on the impact of the role of voluntary organizations on the health and well-being of Canadians.

Some Suggestions for Further Research

This study raises some questions for further research. We have used the term impact and effectiveness as they are commonly used in the literature. Is it necessary to redefine the impact of VHS organizations when dealing with breast cancer? We noted that the impact of these organizations is at two levels. The first level is the macro level—the impact on the disease through research and policy advocacy. The second impact is at the micro level on women (and their families) who either have the disease or are likely to contract the disease. Is this two-fold division of impacts sufficient? Does impact measurement need to be more finely divided to get a better picture of the impact of VHS organizations?

We have suggested comparative assessment on incidence, mortality and morbidity rates across regions differentiated by access to VHS organizations. This is certainly meaningful at the micro level. Does this have an impact at the macro level? Does it matter where the research/advocacy takes place?[17] Furthermore, to understand impact more fully it is necessary to understand what happens at VHS organizations over time. Longitudinal studies to assess the growth in the VHS organizations in the face of changing information on the disease and changes in responses to the various stake-holders (researchers, advocates, women with breast cancer, caregivers, etc.) will be required to give a more accurate picture of effectiveness and impact.

[17] A study by O'Brecht, & Doutriaux (1992) shows how the distribution of health research funding varies by region in Canada and the authors question its effects.

There is one more relevant question. What modifications are necessary to apply this framework to VHS organizations dealing with other diseases?

Appendix I: VHS Organizations and Breast Cancer

In this appendix we list the various organizations that deal with many aspects of breast cancer, including: research in the prevention and cure; the treatment, support and care for persons with breast cancer and their families and friends; information dissemination and coordination; and, advocacy. We primarily are dealing with VHS organizations in the Greater Toronto Area. This may include national, provincial and local grassroots organizations that are accessible to individuals in this area.

We have also included a very short section on virtual VHS organizations such as list serves and Web sites. Due to the blurring of spatial boundaries for electronically provided information and the hundreds of available sites, we have simply given a few sites as examples. The list is by no means comprehensive. Where possible we have included Web sites for the VHS organizations listed.

We list the VHS organizations as follows:

1. National Organizations
2. Provincial Organizations
3. Local Organizations in the Greater Toronto Area
4. Virtual VHS Organizations available via the Internet.

1. National Organizations

1. **Canadian Breast Cancer Foundation** www.cbcf.org
   790 Bay St, #1000, Toronto, ON M5G1N8

   Objectives: to focus on prevention (early detection and early diagnosis, to raise awareness through education and information, to support and encourage the advancement of breast cancer research, to encourage self responsibility for breast health); body awareness with a health promotion message; to provide a Canadian health promotion framework for a breast health message for all women and for all health care professionals; and, to facilitate a multicultural outreach program for all women and health care professionals.

2. **CBCRI - Canadian Breast Cancer Research Initiative –**
   10 Alcorn Avenue, Suite 200, Toronto ON M4V 3B1 Tel.: (416) 934-5671

   In 1998, the Canadian Breast Cancer Foundation joined the Canadian Breast Cancer Research Initiative (CBCRI), a unique coalition of seven public, private and nonprofit organizations funding breast cancer research in Canada. Through pooled resources, the CBCRI funds a broad spectrum of research in prevention, early detection, treatment, quality of life, health services and laboratory investigations.

3. **CBCI - Canadian Breast Cancer Initiative:**
http://www.hc-sc.gc.ca/hppb/ahi/breastcancer/

(This is a federal government initiative with a partnership with other VHS organizations such as Canadian Breast Cancer Foundation, Canadian Breast Cancer Network, Canadian Cancer Society, Medical Research Council of Canada, and the College of Family Physicians of Canada, etc.)

The objectives of the CBCI are to reduce the incidence of breast cancer, reduce mortality as a result of breast cancer and improve the quality of life of those affected by breast cancer and their support networks. In particular its objectives are: Prevention, Early Detection and Quality Screening of Breast Cancer; Surveillance and Monitoring of Breast Cancer; Quality Approaches to Breast Cancer Diagnosis, Treatment and Care; Community Capacity-Building; and, Coordination and Evaluation

4. **CHN - Canadian Health Network**
P.O.Box 45115, 2482 Yonge St. Toronto ON (416) 244-1443

CHN provides a single-access window to the resources of a growing network of partners. The federal government supports the development of a Canadian Health "Info-structure" to make it easier for consumers to access health information. This initiative has included projects such as an electronic national health surveillance network and a health information system tailored to the needs of First Nations.

5. **Canadian Cancer Society (CCS) – Ontario Division** www.ontario.cancer.ca
10 Alcorn Ave, #200 Toronto, Ontario M4V 3B1 (416) 961-7223

This national community-based organization provides services to people living with cancer, including transportation, support groups, information and financial assistance for drugs and wigs. It also provides the following:
Cancer Information Service: The Canadian Cancer Encyclopaedia (CCE): detailed information about cancer, the different treatments, therapies, products and services.
Reach for Recovery
Cancer information service 1-888-939-333
Self-help groups providing emotional and social support, practical help and guidance. Toll free telephone: 1-800-263-6750: patients matched with trained volunteer survivors.
Clinic and Lodge Programs: support for patients and families while receiving treatment
Cancer Connection
Providing support by matching cancer patient with someone over the phone who has experienced the same kind of cancer or similar situation

6. **Breast Implant Information Line of Canada**
   56 Touraine Ave. Toronto, ON M3H 1R2

   National support and self-help group for women who had silicone gel breast implants.

7. **National Cancer Institute of Canada** www.ncic.cancer.ca

   The National Cancer Institute of Canada acts with its partner, the Canadian Cancer Society, and with the Terry Fox Foundation to provide support for cancer research and related programs undertaken at Canadian universities, hospitals and other research institutions.

8. **The Canadian Breast Cancer Network** www.cbcn.ca
   1-800-685-8820

   From its inception in 1994, this network has worked for the participation of breast cancer advocates at all levels of decision-making regarding breast cancer policy and research in Canada.

9. **Look Good Feel better** – www.lgfb.ca, www.lookgoodfeelbetter.ca

   Helping women manage the appearance-related side effects of their cancer treatment, Look Good Feel Better (a registered charity) offers workshops, literature and information on makeup, hair alternatives, skin and nail care. This national public service program is an initiative of the member companies of the Canadian Cosmetic, Toiletry and Fragrance Association. Since 1992, Look Good Feel Better has assisted more than 300,000 Canadian women living with cancer. Over 1000 volunteers from cosmeticians, estheticians, wig specialists, and lay volunteers donate their time to this program. It has 65 permanent workshop sites in major cancer care centres across the country.

10. **Dragon Boat racing** www.dragonsabreast.org

    The purpose is to encourage women with breast cancer to lead full and active lives, to demonstrate the overwhelming benefits of rehabilitation and recreational exercise for women recovering from breast cancer, to encourage women of all ages and physical ability to participate in some form of physical activity, such as dragon boating to raise awareness about breast cancer, to be a support for other team members, and to have FUN! Breast cancer teams have formed in over 20 communities across Canada.

2. Provincial Organizations

1. **Cancer Care Ontario** www.cancercare.on.ca
   416-971-9800 –

   Provides services to cancer patients including screening program for breast cancer

2. **Ontario Breast Cancer Information and Exchange Project**
   2075 Bayview Ave., Toronto, ON M4N 3M5 (416) 480-6002

   Coordinating information available on breast cancer, provides access to information by women and families and health professionals.

3. **Ontario Breast Screening program**
   1-800-668-9304

   Operates breast cancer screening centers at 10 locations (plus seven affiliated sites) in the Province

Hamilton	Kingston	London	North York	Ottawa
Scarborough	Sudbury	Thunder Bay	Toronto	Windsor

   With affiliated sites

Cambridge	Guelph	Owen Sound	Pembroke
Peterborough	Renfrew	Sault Ste. Marie	

4. **Ontario Cancer Treatment and Research Foundation**
   620 University Ave, Toronto ON M5G 2L7
   (416) 971-9800

   Responsible for cancer treatment and delivery in Ontario, this foundation maintains and gathers data about cancer incidence rates and statistical information. Operates eight Cancer Centres in Ontario.

5. **Breast Cancer Research and Education Fund (Ontario)**
   8 Pearl Ann Drive
   St. Catherines, ON L2T 3B3 (905) 687-3333

6. **Patients Rights Association**
   170 Merton St
   Toronto, ON
   (416) 487-6287

7. **Cancer Information Service –1- 800-263-6750**
   This toll-free line provides information about all forms of cancer related issues.

8. **Interlink Community Cancer Nurses** www.interlinknurses.on.ca
   620 University Ave, #701, Toronto On M5G2C1 416-599-5645

   This nonprofit community based agency provides nursing assistance to cancer patients and thin families care and support at all stages of their illness

9. **Breast Cancer Action**
   613-736-5921

   This is a survivor-led independent charitable organization working to educate and support women and men living with breast cancer, their families and the community

10. **Community Hospice Association of Ontario**
    40 Wynford Drive, #313, Toronto (416) 510-3880

11. **Hospice Association of Ontario** www.hospice.on.ca
    Hospice care in more than 90 communities.

12. **Assistive Devices Program**
    1 -800-268-6021
    Funding for breast prostheses.

13. **Willow: Ontario Breast Cancer Support Group and Resource Centre**
    www.willow.org
    785 Queen Street East, Toronto, ON M4M 1H4-Toll free 1-888-778-3100

    Provides information, support and referrals to persons with breast cancer, families and friends; emotional support through trained volunteers who have experienced breast cancer, services in many languages, links to a network of breast cancer support groups, personalized research and information packages.

14. **Wellspring** http://www.wellspring.ca
    Breast Cancer Support Groups, access to information, and opportunities to develop self-help skills and coping strategies to enhance quality of life.
    Multiple locations:
    The Coach House; 81 Wellesley St. East, Toronto, ON
    2075 Bayview Ave. Toronto ON
    2545 Sixth Line, Oakville, ON
    231 Hyman Street, London, ON
    3250 Schmon Parkway, Thorold ON

15. **Victoria Order of Nurses (VON)**

    Home visiting for breast cancer patients after surgery.

3. Local Organizations in the Greater Toronto Area (G.T.A.)

Support Groups

1. AJAX-PICKERING **Living with Breast Cancer**
   Phone (905) 686-1516

2. BARRIE - **Reach** c/o Canadian Cancer Society
   Phone (705) 726-8032 Phone 1-800-338-6610

3. BRAMPTON **Breast Cancer Support Group**
   Phone (905) 451-4460

4. BURLINGTON **Breast Cancer Support Services**
   Burlington, Hamilton, and Oakville Chapters
   Phone (905) 634-2333 Phone 1-800-465-1902
   E-mail: mailbox@breastcancersupport.org

5. HAMILTON **Burlington Breast Cancer Support Services**
   Phone (905) 634-2333 Phone 1-800-465-1902
   E-mail: mailbox@breastcancersupport.org

6. MARKHAM - **Connecting Rainbows**
   Phone (905) 471-5878

7. MILTON **Breast Cancer Support Group**
   Phone (905) 878-2573

8. MISSISSAUGA **Breast Cancer Support Group**
   Phone (905) 608-8411

9. NEWMARKET - **Connecting Rainbows**
   Phone (905) 853-9773 E-mail: fletcher@fletcherfcm.com

10. OAKVILLE Breast **Cancer Support Services**
    Phone (905) 844-6651

11. ORANGEVILLE - **Orangeville-Dufferin Breast Cancer Support Group**
    Phone (519) 855-4914

12. OSHAWA and **District Breast Cancer Support Group**
    c/o Hearth Place Phone (905) 579-1998 and (905) 579-4833
    Web site: www.hearthplace.org

13. STOUFFVILLE - **Connecting Rainbows**
Phone (905) 642-2329 (Sally)

14. TORONTO - **Breast Cancer Support for Immigrant Women**
Phone (416) 515-8423
E-mail: hema_abeygunawardena@tednet.oise.utoronto.ca

15. TORONTO - **Bayview Support Network**
Phone (416) 480-6898

16. TORONTO - **Etobicoke Breast Cancer Support Group**
Phone (416) 239-6009 E-mail: drfager@iprimus.ca

17. TORONTO - **Hispanic Women's Support Group**
Phone (416) 516-0851

18. TORONTO - **Ismali Cancer Support Network**
Phone (416) 491-9320

19. TORONTO - **L'Chaim Health Cancer Support Group for Jewish Women**
Phone (416) 633-0409

20. TORONTO - **Scarborough Breast Cancer Support Group**
Phone (416) 431-3438

21. TORONTO - **Saint Paul's Centre Cancer Support Group**
(Chinese Speaking) Phone (416) 493-3333

22. VAUGHAN **Living with Breast Cancer**
Phone 905-770-1144 or 800-567-4324

23. **St. Stephen's Community House**
169 Brunswick Ave, Toronto ON www.ststephenshouse.com

Provides wellness promotion programs and offers workshops and information on breast health.

24. **Alliance of Breast Cancer Survivors**
Box 2035; 20 Eglinton Avenue West, Toronto, ON

Support group, survivor-driven; dedicated to changing the status of breast cancer treatment; research & education.

25. **FOR US Mississauga Breast Cancer Support Group**
1140 Burnhamthorpe Road West, #106, ON L5C 4E9
905-896-3200

Hospital Affiliated Centres:

26. Mount Sinai Hospital: **Marvelle Koffler Breast Centre**

Provides Breast imaging, surgical, oncology, psychosocial services, Familial breast clinic, resource centre, boutique complementary health programs including yoga, reflexology, art therapy and Reiki.

27. Ontario Cancer Institute- Princess Margaret Hospital (University Health network)

Mindfulness -Based Stress Reduction
Psychosocial oncology program
Healing Journey program (www.healingjourney.toronto.on.ca)
Patient education Programs

28. St Michael's Hospital: **The Breast Centre** www.sssmh.toronto.on.ca

Provides screening, program, diagnostic clinic, oncology services

29. North York General Hospital www.nygh.on.ca
Bank of Montreal/Nesbitt Burns Breast Diagnostic Centre
The Royal Bank Financial group Education Centre

Provides diagnostic and referral services and educational resources.

30. Toronto-Sunnybrook Regional Cancer Centre**: Bayview Support Network**
2075 Bayview Ave., Toronto, ON http://www.tsrcc.on.ca\bsn

Drop-in meeting twice per month; numbers vary; meetings led by volunteers.

4. Virtual VHS Organizations

Several hundred sites exist. Below are a few examples.

Internet sites: www.thebreastcaresite.com, www.healthtalk.com, www.breastcancer.net, www.cancernews.com, www.breastcancerinfo.com, www.canceranswers.org www.nabco.org, www.nationalbreastcancer.org, www.cancer.org.

Listserve: Discussions among breast cancer patients, their families and friends, and caregivers. Listserve@morgan.UCS.MUN.ca

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An Inventory of Past Research on the Voluntary Health Sector in Canada

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November 4, 2001

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The opinions expressed in this paper reflect the views of the authors and do not necessarily reflect those of Health Canada or the Government of Canada.

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An Inventory of Past Research on the Voluntary Health Sector in Canada

A- Introduction

This report provides an assessment of the research environment on the Voluntary Health Sector (VHS) in Canada. A broad-based index analysis resulted in collection of information on 101 Journal articles, 26 books and manuscripts, 6 conference papers, 10 unpublished Ph.D. dissertations and Master's theses and a sample of 7 newspaper and magazine articles that focused on the VHS in Canada.

The main objective of the report is to classify the research findings in terms of publication categories. Within each category a further analysis with regards to the subject of publication is undertaken. Subject analysis establishes a major analytical tool in terms of understanding the research gap that exists in the VHS in Canada, while at the same time presents an opportunity to develop sensible proposals to remedy the situation.

Aside from the subject analysis, the report provides a list of journals that the researchers used as a venue to disseminate their research findings. The inventory of Journals provides valuable information that could be used in guiding researchers who are commissioned to undertake research on VHS in Canada by the Ministry of Health and any other organization. Journals such as *Social Science and Medicine*, *Canadian Journal of Public Health*, *Canadian Medical Association Journal* and *Journal of Community Health* are important venues of publication that could be contacted during and upon the completion of commissioned work for publication.

The report also provides a sense of how the inventory of publications is compiled. Furthermore, the list of major indexes provides additional guidance for future analyses on VHS-related journal scanning as well as any other literature survey on the health sector in general.

The report concludes with a limited number of recommendations to further the study of VHS in Canada. Based on the observations of the analyst, such recommendations will mainly focus on creating and sustaining an academic research interest in the field as well as some practical guidelines.

The report is organized as follows: a summary of findings is presented in the next section (B); Section (C) deals with the subject analysis in both analytical aspects and numerical analysis; in Section (D) a list of publication venues are given, followed by Section (E) where the major publication indexes are presented. Conclusions and recommendations are presented in Section (F). A full list of publications is given in Appendices 1 through 5.

B- A Summary of Findings

As noted above, this section presents a summary of literature scanning. Table 1 classifies publications on the VHS in Canada in terms of the type of publications from 1971 onwards. A 10-year time dimension is provided in order to get a better understanding of time distribution of past research on the subject.

Table 1. Classification of Publications (type/time frame)

	Time Frame				Total
Type	2000s	1990s	1980s	1970s	71-01
Journal	25/ 25%	65/ 65%	9/ 9%	2/ 2%*	101/ 100%
Books	4/ 15 %	15/ 58%	4/ 15%	3/ 12%	26/ 100%
Conference	-	3/ 50%	3/ 50%	-	6/ 100%
Disser./The.	-	8/ 80%	1/ 10%	1/ 10%	10/ 100%
NP/Mag.	-	7/ 100%	-	-	7/ 100%
Total	29/ 19%	98/ 65%	17/ 11%	6/ 4%*	150/ 100%

* Percentages don't add up to 100% due to rounding.

Quick-Reference: Numbers

- Literature scan has produced 150 publications in total.
- 67 percent of all publications that the literature scan has produced are journal articles, 17 percent are books and manuscripts, 7 percent dissertations/theses, 5 percent newspaper/ magazine items and 4 percent conference papers.
- 65 percent of all journal articles were published in the 1990s, and 25 percent were published in the last two years. It seems to be the case that the interest in the field is increasing. (Assuming that the level of publications in the 2000s continues at the same speed, one can extrapolate that in the next 8 years we can expect to see at least another 100 journal articles on the VHS in Canada.)
- The percentage of journal articles published in the 1990s is equal to the percentage of total publications published in the 1990s.

Figure 1. Distribution of Publications (Type/time-frame)

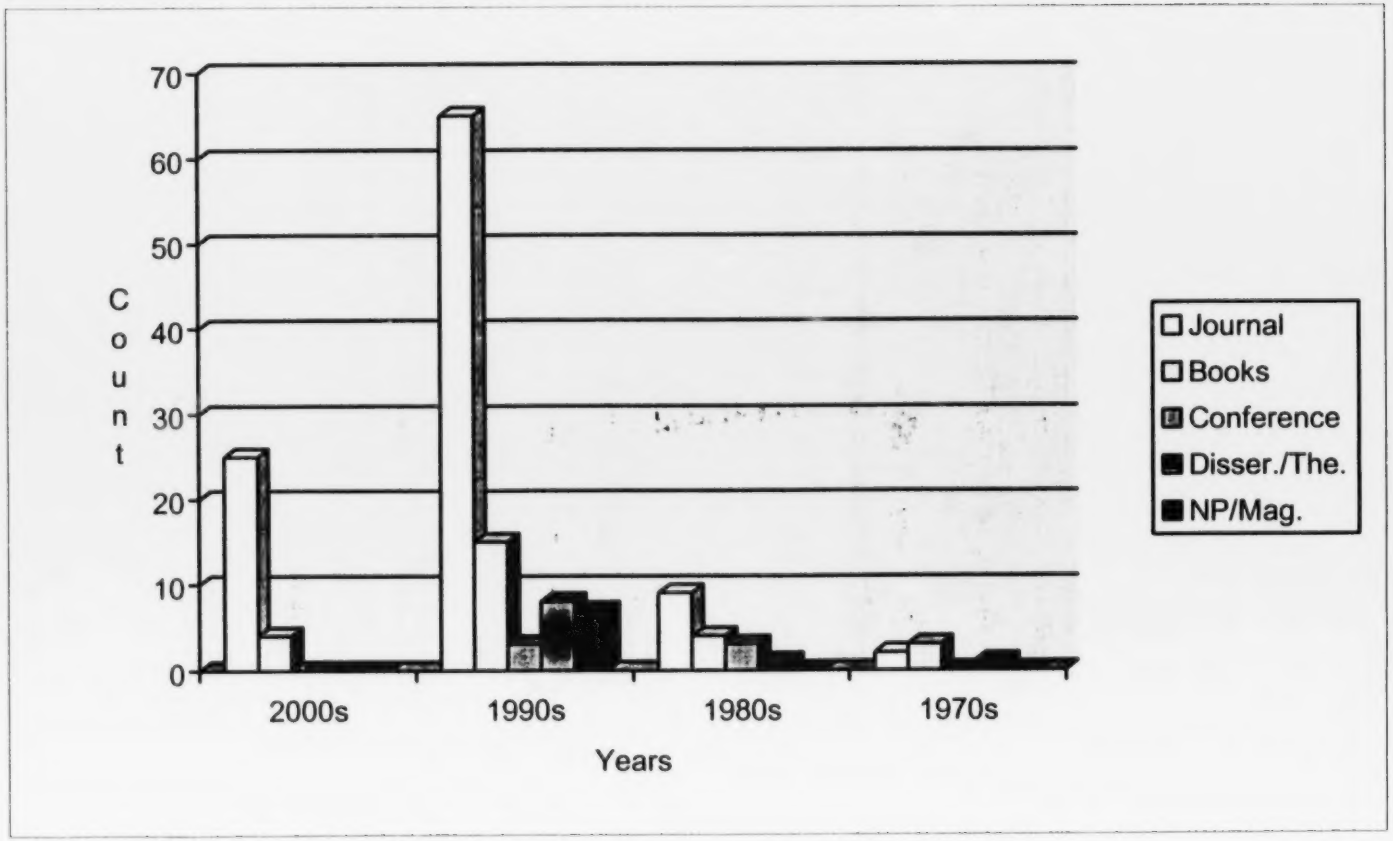
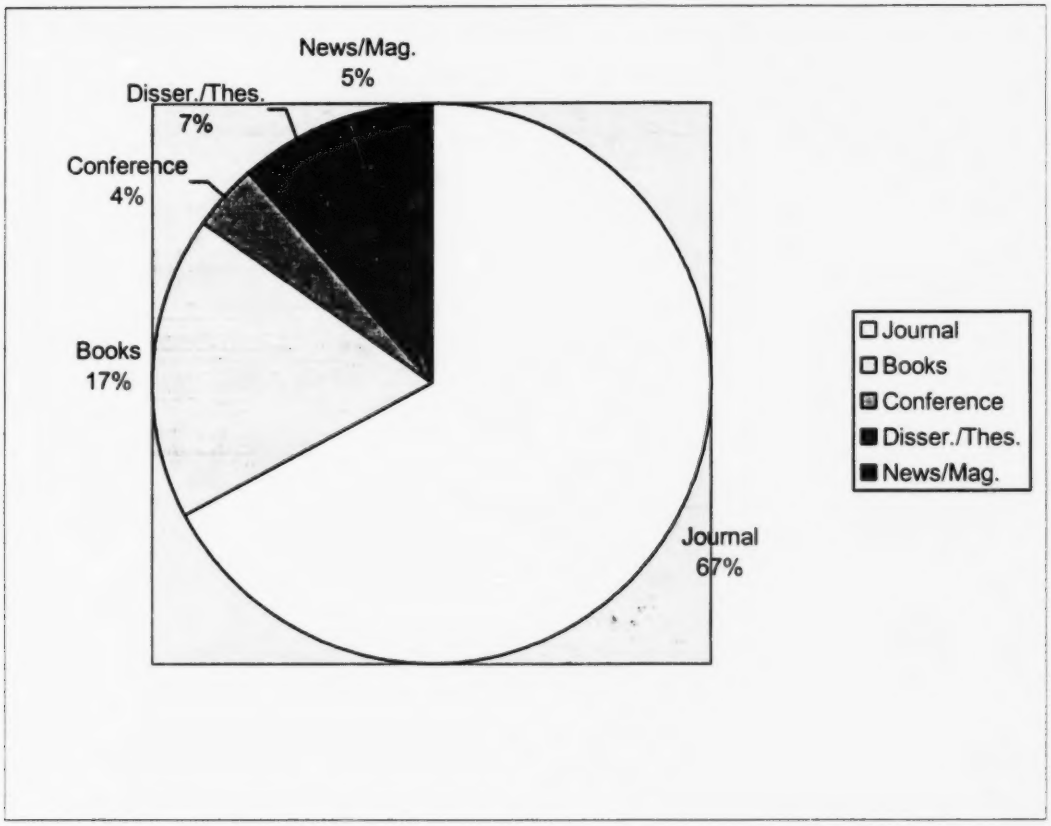


Figure 2. General Distribution of Publications



C- Subject Analysis: Analytical Issues

At an analytical level, subject analysis creates two main taxonomies: organizational dimension, and functional dimension. Within the organizational dimension, the report classifies publications in terms of a) studies focused on one or more of the general aspects of the VHS in Canada (VHSG); b) organizational case studies (OCS); and d) other VHS related studies (VHS-Rel). In a similar vein, the functional dimension attempted to classify the past research with respect to a) services and service delivery (S-SD); b) general policy related issues (GPRI); and c) health promotion and education (HPE).

1. Organizational Dimension:
    a) VHSG: studies that focused on one or more general aspects of the VHS are coded under this subcategory. Ranging from organizational aspects of community health centers to health sector reform specifically dealing with the VHS, many studies reflected upon at least one organizational aspect. Classification is generally based on the information provided in abstracts

whenever available. In the absence of an abstract, the title and/or keyword information is used.

b) OCS: Organizational case studies were very common; despite the fact that they provided some general information on the VHS in general, it is important to put case studies in a category of their own simply due to their scope and limitations resulting from methodological approach.

c) VHS-Rel: Some of the studies focused on the health sector in general with some attention to VHS. This subcategory is created in order to reflect the fact that the relevancy was significant even though the study was not particularly dealing with the VHS as such.

2. Functional dimension:

a) S-SD: VHS literature often dealt with health services and delivery of such services by community health organizations. Outcomes measurement, effectiveness/efficiency evaluation, service history and dissemination of experience-based knowledge, many studies were in fact designed to produce knowledge on the basis of the functions of VHS organizations within the general frame of the health sector in Canada.

b) GPRI: Often researchers were discussing a policy related issue both in the sense of health policy and the role of VHS organizations, and particular managerial, financial and technical aspects of the functioning of VHS organizations. In this case, functional dimension means that particular publications bring out a macro-functional aspect of the VHS in a general policy framework and a micro-functional aspect in terms of organizational policy-making.

c) HPE: This subcategory intends to separate studies that particularly deal with health promotion and education functions of VHS organizations, as such analyses provide a further functional dimension to the role of VHS organizations within the health sector in general.

A numerical distribution of publications across organizational dimension is presented in table 2.

Table 2. Distribution of Publications: Organizational Dimension

Type	VHSG	OCS	VHS-Rel	Total
Journal	56/ 55%	39/ 39%	6/ 6%	101
Books	16/ 62%	6/ 23%	4/ 15%	26
Conference	1/ 17%	5/ 83%	-	6
Disser./The.	7/ 70%	3/ 30%	-	10
NP/Mag.	1/ 14%	6/ 86%	-	7
Total	81/ 54%	59/ 39%	10/ 7%	150

Quick Reference: Numbers

- More than half of the publications focused on at least one aspect of the VHS in general (54 percent). 39 percent of the publications were case studies that focused on at least one organizational aspect of the VHS organization under review.
- 55 percent of the journal articles were focusing on VHS in general, 39 percent were case studies.
- Dissertations/theses were mainly dealing with general aspects of VHS organizations; this is surprising since such studies mainly focus on case studies, as they are more manageable in terms of time and financial restrictions in post-graduate education.
- A majority of books and manuscripts were confined to at least one of the general characteristics of VHS organizations. This may prove to be productive if further studies follow the same pattern as books and manuscripts are more theory-oriented and there exists a major semantic confusion in classification and definition issues concerning the VHS.
- Most of the conference papers are case studies; this seems to be normal in this type of publication. Conference papers are generally limited in scope and conferences are generally theme oriented.

Classification of publications with respect to functional orientation is presented below.

Table 3. Distribution of Publications: functional dimension

Type	S-SD	GPRI	HPE	Total
Journal	48/ 48%	47/ 47%	6/ 6%	101
Books	14/ 54%	12/ 46%	-	26
Conference	1/ 17%	2/ 33%	3/ 50%	6
Disser./The.	4/ 40%	6/ 60%	-	10
NP/Mag.	2/ 29%	4/ 57%	1/ 14%	7
Total	69/ 46%	71/ 47%	10/ 7%	150

Quick reference: Numbers

- There seems to be an equal distribution among the publications in general with respect to functional aspects of services and service delivery (46 percent) and general policy related issues (47 percent).
- The distribution of journal articles follows the same pattern, services and service delivery 48 percent and general policy-related issues 47 percent.
- A majority of conference papers are related to health promotion and education; again, this is due to the nature of academic work related with conferences in general.
- 60 percent of all dissertations/theses are devoted to general policy related issues. This is in line with the general trend in the organizational dimension, in which we observe a majority of such publications devoted to general issues.
- A majority of books and manuscripts focused on services and service delivery (54 percent), which is closely followed by general policy-related issues (46 percent).

D- List of Publication Venues (specific to journal articles)

A list of journals is presented in Table 4 with specific reference to the number of publications published in respective journals. This list may provide a rough guide in terms of further research publications, as it presents a wide array of institutions that have published work on VHS in Canada so far. Only those journals that published at least two articles are included in the list. A complete list can be found in Appendix 1, which presents the total inventory of journal articles.

Table 4. List of Journals

Name of the Journal	No. of Articles.
Social Science and Medicine	8
Canadian J. of Public Health	5
Canadian Medical Association J.	5
J. of Community Health	3
WE International	3
International J. of Health Services	2
Public Health Nursing	2
Sociologie du Travail	2
Health Care Management Review	2
Health and Place	2
Community Mental Health J.	2
Northern Ontario Business	2
J. of Epidemiology and Community Health	2
Canadian J. on Aging	2

It seems to be the case that there are a wide variety of venues for academic/professional publication on the VHS in Canada. American academic journals have also published Canadian material (as presented in Appendix 1). *Social Science and Medicine*, *Canadian Journal of Public Health* and *Canadian Medical Association Journal* deserve special attention. Researchers may be advised to contact the editors of such journals, even during the initial phases of their research, to introduce the subject matter of the study and how it relates to the area in which the journal publishes material.

E- List of Publication Indexes as Sources of Literature Scan

The following are the major social science and science indexes where the researcher compiled the inventory of past research on the VHS in Canada. Social Science Citation Index (SSCI) is one of the major sources of scientific information pertaining to humanities and social sciences in the world. The Institute of Scientific Information's SSCI contained more than 7.5 million entries as of November 2001, covering the years between 1995 and 2001. The previous years (1971 through 1995)

were covered in hard-copy indexes that could be found at any university library (in this case Carleton University Library). Gov-Info-Canadian Research Index (CRI) covered journal articles published 1982 through 2001; Public Policy PAIS International is a collection of public policy related material since 1972; Social Work Abstracts indexed publications in this area since 1977 and Canadian Business and Current Affairs-CRI, covers Canadian-specific material published since 1982. These are some of the examples that should provide an understanding of the coverage of literature scanning.

The keywords and phrases that that are used in scanning were provided to the researcher along with the project proposal. The list of items proved to be efficient in producing VHS-related publications as search outcomes.

The list of major indexes included:

- Social Science Citation Index (SSCI)
- CUBE (Carleton University Bibliographic Enquiry)
- Canadian Research Index (CRI)
- Canadian Business and Current Affairs (CBCA)
- Gov-INFO (Sub-index of CRI)
- PsycLIT
- Public Policy PAIS International
- Social Work Abstracts
- Cambridge Scientific Abstracts (CSA)
- Conference Papers Index
- EconLIT
- ERIC
- Social Services Abstracts
- Sociological Abstracts
- Worldwide Political Science Abstracts
- PUBMED
- AIDSEARCH
- MEDLINE
- CISTI
- Web of Science
- Wilson Indexes
- PAIS.

F- Conclusions and Recommendations

The past research on the VHS in Canada has produced 150 publications in total. It must be noted that the newspaper magazine articles should be considered only as a sample of the available work. However, this caution has little to do with the academic research environment, as newspaper/magazine coverage is generally sporadic and has little to do with the organizational aspects of the VHS in general. Academic journals have published

101 articles during the time frame covered by the literature scan (1971 through 2001), and such publications were condensed in the 1990s and 2000s. Another observation was the relatively late attempts to provide a theoretical background in understanding the organizational aspects of VHS in Canada, which are provided in manuscripts written by Febbraro et al., and Legowski and Albert. (Both were written for the VHS project.)

The major problem in terms of the publication gap seems to be the lack of a continued effort to create and sustain academic interest in the field. This could be done in a variety of ways.

First, a conference on VHS in Canada should be organized. As noted above, conferences prove to be topical and theme oriented, and organizing a conference may prove to be a good way to raise some interest in academic circles. The Ministry can call such a conference itself or invite a group of scholars from a number of universities to form a consortium that would define the parameters of the conference (theme-topic) and design the process inviting submissions. As always, a conference may prove to be difficult to organize, requiring large sums of financial resources. In this case, stakeholders (federal and provincial departments and major voluntary organizations) may find a way to share costs. A topical conference may be effective on its own even as a one-shot event, however, periodic conferences have proven to be very effective in sustaining academic interest; in this case, a long-term commitment may be required for organizing annual events, each dealing with a particular aspect of the VHS.

Second, there seems to be a good number of dissertations/theses on the VHS in Canada. The authors of the most recent dissertations may be contacted to find out if there is any determination to publish such material. If so, a partial funding arrangement may be found.

Third, one of the most important aspects of creating and sustaining academic interest has to do with academicians themselves. In this sense, a scholarship funding arrangement on topical analysis of VHS in Canada should be announced. Most Ph.D. students live in dire financial circumstances; there are many funding resources (such as the Millennium Foundation and SSHRC) but these resources require proposals in social science in general. A topical financial assistance scheme might draw attention from would-be scholars who are interested in doing research on the VHS. Such an arrangement would have a long-term research commitment on the part of the receiver of the funding, as the academic world works on the basis of specialization and compartmentalization.

Lastly, a research competition can be announced. In this case the participants may be asked to contribute to the understanding of the role of the VHS in the Canadian health system. Financial incentives may draw attention, albeit limited, from academic and professional circles that are interested in health policy in general.

Appendix 1 – Journal Articles

1.

Title	Developing and testing instruments to measure client outcomes at the Comox Valley Nursing Center
Author(s)	Hilton, BA; Budgen, C; Molzahn, AE; Attridge, CB
Journal	PUBLIC HEALTH NURSING
Pub. Date	2001, SEP-OCT, v.18
Pages	327-339
Abstract	A Nursing Centre in Canada was initiated to demonstrate nursing practice in a primary health care context, unencumbered by conventional health care agency parameters. As one part of a multi-method evaluation, a 5 instrument client questionnaire was designed. The main instrument was developed by the researchers to measure the impact of the Centre and nurses' work from the perspective of clients. No established instrument could be found that was appropriate for the Centre's diverse client population and nature and variation in outcomes. To guide the development of the new instrument, minimally structured client interviews were conducted with 15 clients. To assess the validity and reliability of other selected instruments for the population, clients were asked to comment on the appropriateness of items. Based on findings, the Nurses' Work and Client Outcomes Questionnaire (NWCOQ) was developed, the Client Satisfaction Questionnaire and demographic questions modified, and a Cantril Self-Anchoring ladder to assess health status was supported for use. An open section was added to invite further description of clients' experiences, in particular, the unexpected, contrary or outstanding. Further pilot work was done and the refined five instrument questionnaire then was used to survey all clients who used the Centre during a seven month period. Findings from the NWCOQ revealed the nature of the nurses' work and the degree change occurred for clients on multiple health dimensions: physical, emotional, managing their situation, and group and community involvement. Clients were highly satisfied with the Centre and experienced many positive outcomes. The quantitative instruments and results were examined in relation to results from other data collection approaches and data sources. The NWCOQ has evidence of content validity and internal consistency reliability. The use of qualitative methods to develop and refine quantitative instruments for assessment of health outcomes for diverse client populations is highly recommended. This strategy is feasible even when outcome measurement timeframes are short.

2.

Title	Northern initiative for social action: An occupation-based mental health program
Author(s)	Rebeiro, KL; Day, DG; Semeniuk, B; O'Brien, MC; Wilson, B
Journal	AMERICAN JOURNAL OF OCCUPATIONAL THERAPY
Pub. Date	2001, SEP-OCT v.55/5
Pages	493-500
Abstract	Northern Initiative for Social Action (NISA) is a consumer-run, occupation-based, nonprofit organization located in northeastern Ontario, Canada. The NISA organization has grown in response to research revealing few opportunities for participation in personally meaningful and socially valued occupation for persons with mental illness living in the community of study. This article describes a mixed-design research study conducted by the ParNorth Research Unit of NISA and an occupational therapist. The study purposes were to (a) better understand the emerging characteristics of the NISA program and identify which the participants found helpful; (b) evaluate whether participation in NISA improved members' quality of life, and (c) ascertain whether participation reduced members' need for more traditional and costly methods of care (e.g., hospitalization, crisis services). Focus groups, daily participant observation, a quality of life interview, a consumer member survey, and objective review of hospitalization data were used for data collection. Qualitative results indicated that NISA helped to meet participants' being, belonging, and becoming needs. Quantitative data indicated that overall, NISA members perceive an improvement in their subjective quality of life and sense of well-being. Their perceptions are supported by minimal use of crisis services and hospitalization, improved socioeconomic status, and several members' success in obtaining paid employment either within or outside NISA. Future challenges include the need to clearly describe the evolving NISA model and to ensure that the growth of this new organization does not exceed secured human or fiscal resources.

3.

Title	Promoting social responsibility for health: health impact assessment and healthy public policy at the community level
Author(s)	Mittelmark, MB
Journal	HEALTH PROMOTION INTERNATIONAL
Pub. Date	2001, SEP v.16/3
Pages	269-274
Abstract	The 1997 Jakarta Declaration on Health Promotion into the 21st Century called for new responses to address the emerging threats to health. The declaration placed a high priority on promoting social responsibility for health, and it identified equity-focused health impact assessment as a high priority for action. This theme was among the foci at the 2000 Fifth Global Conference on Health Promotion held in Mexico. This paper, which is an abbreviation of a technical report prepared for the Mexico conference, advances arguments for focusing on health impact assessment at the local level. Health impact assessment identifies negative health impacts that call for policy responses, and identifies and encourages practices and policies that promote health. Health impact assessment may be highly technical and require sophisticated technology and expertise. But it can also be a simple, highly practical process, accessible to ordinary people, and one that helps a community come to grips with local circumstances that need changing for better health. To illustrate the possibilities, this paper presents a case study, the People Assessing Their Health (PATH) project from Eastern Nova Scotia, Canada. It places ordinary citizens, rather than community elites, at the very heart of local decision-making. Evidence from PATH demonstrates that low technology health impact assessment, done by and for local people, can shift thinking beyond the illness problems of individuals. It can bring into consideration, instead, how programmes and policies support or weaken community health, and illuminate a community's capacity to improve local circumstances for better health. This stands in contrast to evidence that highly technological approaches to community-level health impact assessment can be self-defeating. Further development of simple, people-centred, low technology approaches to health impact assessment at the local level is called for.

4.

Title	Understanding the role of contextual influences on local health-care decision making: case study results from Ontario, Canada
Author(s)	Abelson, J
Journal	SOCIAL SCIENCE & MEDICINE
Pub. Date	2001, SEP v.53/6
Pages	777-793
Abstract	Approaches to involving the public in local health care decision making processes (and analyses of these approaches) have tended to treat participation and publics uniformly in search of the ideal method of involving the public or providing the same opportunities for public participation regardless of differing socio-economic, cultural, institutional or political contexts within which decisions are made. Less attention has been given to the potential for various contextual factors to influence both the methods employed and the outcomes of such community decision-making processes. The paper explores the role that context (three sets of contextual influences more specifically) plays in shaping community decision-making processes. Results from case studies of public participation in local health-care decision making in four geographic communities in Ontario are presented. During the study period, two of these communities were actively involved in health services restructuring processes while one had recently completed its process and the fourth had not yet engaged in one. Several themes emerge from the case studies regarding the identification and role of contextual influences in differentially shaping participation in local health care decision-making. These include the propensity for communities with different social and structural attributes to engage in different "styles" of participation; the importance attached to "community values" in shaping both the qualitative and quantitative aspects of participation; the role of health councils, local government and inter-organizational collaboration as participation "enablers"; and the politicization of participation that occurs around contentious issues such as hospital closures.

5.

Title	A critical examination of community-based responses to household food insecurity in Canada
Author(s)	Tarasuk, V
Journal	HEALTH EDUCATION & BEHAVIOR
Pub. Date	2001, AUG v.28/4
Pages	487-499
Abstract	Over the past two decades, household food insecurity has emerged as a significant social problem and serious public health concern in the "First World." In Canada, communities initially responded by establishing ad hoc charitable food assistance programs, but the programs have become institutionalized. In the quest for more appropriate and effective responses, a variety of community development programs have recently been initiated. Some are designed to foster personal empowerment through self-help and mutual support; others promote community-level strategies to strengthen local control over food production. The capacity of current initiatives to improve household food security appears limited by their inability to overcome or alter the poverty that underpins this problem. This may relate to the continued focus on food-based responses, the ad hoc and community-based nature of the initiatives, and their origins in publicly funded health and social service sectors.

6.

Title	Impact of rural hospital closures in Saskatchewan, Canada
Author(s)	Liu,-Liyan; Hader,-Joanne; Brossart,-Bonnie; White,-Robin; Lewis,-Steven
Journal	SOCIAL-SCIENCE-AND-MEDICINE
Pub. Date	2001, June v.52/12
Pages	1793-804
Abstract	Canada's health care system has undergone major changes since 1990. In Saskatchewan, 52 small rural hospitals funded for less than eight beds stopped receiving funding for acute care services in 1993. Most were subsequently converted to primary health care centers. Since then, concerns have been raised about the impact of the changes on rural residents' access to care, their health status, and the viability of rural communities. To assess the impact of hospital closures on the affected communities, we conducted a multi-faceted, province-wide study. We looked at hospital use patterns, health status, rural residents' perceptions of the impact of these hospital closures, and how communities responded to the changes. We found the hospital closures did not adversely affect rural residents' health status or their access to inpatient hospital services. Despite widespread fears that health status would decline, residents in these communities reported that hospital closures did not adversely affect their own health. Although some communities continue to struggle with changes to health care delivery, others appear to have adapted as a result of strong community leadership, the development of widely accepted alternative services, and local support for creating innovative solutions. Good rural health care does not depend on the presence of a very small hospital that cannot, in today's environment, provide genuinely acute care. It requires creative approaches to the provision of primary care, good emergency services, and good communication with the public on the intent and outcomes of change.

7.

Title	Disadvantaged persons' participation in health promotion projects: some structural dimensions
Author(s)	Boyce,-William-F
Journal	SOCIAL-SCIENCE-AND-MEDICINE
Pub. Date	2001, May v.52/10
Pages	1551-64
Abstract	A structural perspective was used in studying community participation of disadvantaged groups (poor women, street youth, and disabled persons) in health promotion projects. Five community projects in the Canadian Health Promotion Contribution Program were examined in a comparative case study utilizing in-depth interviews, documents, and secondary sources. Analysis revealed relatively low numbers and restricted range of participants, difficulties in recruiting and maintaining participants, declining rates of active participation over time, and limited target group influence and power. This paper reports on the relationship between various dimensions of structure (social-cultural, organizational, political-legal-economic) and the community participation process. Participation was influenced by structural factors such as bureaucratic rules and regulators, perceived minority group rights and relations, agency reputations and responsibilities, available resources, and organizational roles. Control of projects by target group members, rather than by service agencies, was an important overall organizational structural factor which allowed community members to achieve influence in projects. The study concludes that a conceptual model based on structural factors is useful in explaining how key factors from federal and local levels can restrict or facilitate the community participation process.

8.

Title	Efficacy of a nurse-led multidimensional preventive programme for older people at risk of functional decline. A randomized controlled trial
Author(s)	Hebert,-Rejean; Robichaud,-Line; Roy,-Pierre-Michel
Journal	Age and Ageing.
Pub. Date	2001, Mar. v.30/2
Pages	147-53
Abstract	Objective: to verify the efficacy of a multidimensional preventative programme on functional decline of older people. Design: randomized controlled trial. Setting: community of Sherbrooke City, Quebec, Canada. Subjects: a representative sample of individuals aged over 75 living at home and identified to be at risk of functional decline by postal questionnaire (n = 503). Intervention: subjects randomized to the study group (n = 250) were assessed at home by a nurse on 12 dimensions (including medication, depressive mood, risk of falls, hearing). A report of the assessment was sent to the general practitioner with recommendations for interventions. A monthly telephone contact was carried out by the nurse for surveillance and to verify if the recommendations had been applied. Methods: the primary outcome--functional decline--was defined as either death, admission to an institution or increase of [greater or equal]5 points on the disability score of the Functional Autonomy Measurement System (SMAF) scale during the reference year. Secondary outcomes were functional autonomy (on the SMAF), well-being (General Well-being Schedule), perceived social support (Social Provision Scale) and use of health care services. Results: of the 494 subjects who completed the study, 48 (19.6%) of 245 in the study group and 49 (19.7%) of 249 in the control group had functional decline (relative risk 1.00; 95% confidence interval 0.82-1.23). There were no differences between the groups in all secondary outcomes. Conclusions: this study confirms the inefficacy of multidimensional programmes for preventing functional decline in the older population. More effort should be devoted to improving the efficacy of specific interventions for conditions causing functional decline.

9.

Title	An evaluation of contracted palliative care home care services in Ontario, Canada
Author(s)	Williams, AM; Caron, MV; McMillan, M; Litkowich, A; Rutter, N; Hartman, A; Yardley, J
Journal	EVALUATION AND PROGRAM PLANNING
Pub. Date	2001, FEB v.24/1
Pages	23-31
Abstract	As a money-saving strategy, the majority of western countries have been moving away from institutionalized care and gravitating towards a home-based care system. Home care services continue to be promoted and a growing variety of services have become widely available, with palliative care being a recent addition. While this continues to occur, the Ontario provincial government has instigated a number of additional money-saving strategies specific to home care. These include a complete restructuring of how home care services are organized and the emergence of a 'request for proposals process', where for-profit home care agencies compete together with not-for-profit agencies to win one of the numerous public contracts available through one of the province's 43 Community Care Access Centres (CCAC). This paper presents an evaluation of the palliative care services as given by the agencies contracted to do so by the Niagara Community Care Access Centre. Using a multi-dimensional research strategy that includes stakeholder surveys, case manager interviews and client surveys, the evaluation research results allow the Niagara CCAC to make an evidence-based decision regarding the palliative care contract renewal.

10.

Title	Reforming Ontario's Primary Health care System: One Step Forward, Two Steps Back?
Author(s)	Suschnigg, C
Journal	International Journal of Health Services
Pub. Date	2001, v.31/1
Pages	91-103
Abstract	N/A

11.

Title	"It's really hitting home": the home as a site for long-term health care (Canada)
Author(s)	England,-Kim
Journal	WE International
Pub. Date	2000, Summer/Fall no48/49
Pages	25
Abstract	The writer discusses the home as a site for long-term health care. She reveals that the Hitting Home Team in Canada is working on providing the first comprehensive description of the Canadian homes in which long-term care services are provided and received. She hopes that the team's findings will interest policy makers in the health, social service, housing, and employment sectors at all levels of government; home care service administrators and providers; housing developers; and advocacy groups.

12.

Title	Where have all the women gone? Ontario Healthy Communities movement
Author(s)	DeSantis,-Gloria
Journal	WE-International
Pub. Date	2000, Summer/Fall no48/49.
Pages	10
Abstract	The Social Planning Council in Ontario, Canada, formed a partnership with Cambridge City Council in 1999 in order to examine where their community was making progress and the areas in which they still needed to do further work. They spoke to almost 150 residents in the community and compiled a series of reports that contained the voices and experiences of women, among others. The Healthy Communities movement is alive and flourishing in Cambridge, and women are playing critical roles in ensuring that this movement continues.

13.

Title	Shaping the movement: women's contributions to Ontario Healthy Communities
Author(s)	Beaudoin,-Monique; Caton,-Lisa; Jacobs,-Anna
Journal	WE International
Pub. Date	2000, Summer/Fall no48/49
Pages	6-9
Abstract	A description is presented of the Ontario Healthy Communities Coalition (OHCC) in Canada, which is part of the international Healthy Communities movement. The OHCC works with community groups, coalitions, and individuals across the province of Ontario to address social, environmental, and economic well-being. Although it is not specifically described as a women's movement, the Healthy Communities movement has been shaped by the strong role that women have played in its development, and its approach promotes the use of tools developed by feminists and employed by many women's groups, such as consensus decision making and participatory evaluation.

14.

Title	Evaluation of telenursing outcomes: satisfaction, self-care practices, and cost savings
Author(s)	Hagan, L; Morin, D; Lepine, R
Journal	PUBLIC HEALTH NURSING
Pub. Date	2000, JUL-AUG v.17/4
Pages	305-313
Abstract	Info-Sante CLSC, the Quebec telenursing service, is a telephone health line nursing service that was implemented in 1995 in every local community service center (CLSC; n = 141) of 15 regional health authorities in the Province of Quebec, Canada. It is, at present, one of the most important first-line health services and it operates in continuity with the other resources in the health and social service system. Info-Sante CLSC operates 24 hours a day, 7 days a week, and received more than 2,260,000 calls in 1997. This article will report the findings from the first province-wide survey of the service, based on a stratified random sample of 4,696 callers. The findings revealed that most respondents were highly satisfied with the service; they followed the nurses' advice and carried out self-care measures as recommended. Nursing interventions helped respondents feel self-reliant, Like they could solve the same or similar problems should they occur in the future. The vast majority of respondents considered that the call they made to Info-Sante CLSC was useful in finding a solution to their problems. The vast majority also claimed that they would certainly call Info-Sante CLSC again should another problem occur. The majority reported they would have turned to another type of resource if Info-Sante CLSC had not existed; half of the respondents stated that they would have used emergency departments and a third would have consulted a doctor in private practice.

15.

Title	Partnering in and for heart health promotion: findings from a survey of community organizations
Author(s)	Elliott SJ, Jolin MA, Walker R
Journal	Can J Public Health
Pub. Date	2000, May-Jun 91/3
Pages	229-33
Abstract	This paper presents the results of a survey conducted with representatives (n = 283) of community health agencies linked to heart health activity in Ontario in order to: 1) describe their levels of involvement in heart health promotion, 2) describe the nature and extent of partnering undertaken in the context of community-based heart health promotion, and 3) assess the extent to which community development approaches vis-à-vis partnering are being employed in Ontario heart health promotion. The survey included a series of questions regarding level of agency involvement in heart health promotion activities organized around four areas: tobacco, nutrition, physical activity and general heart health. Respondents were also asked to report the nature and extent of partnering that took place. Results indicate that levels of involvement varied significantly across activity area and by organization, although every agency type reported some level of involvement in each of the four activity areas. Overall, agencies surveyed continue to employ traditional settings (i.e., schools and community) as well as strategies (i.e., public education) but report a substantial amount of partnering and collaboration when undertaking community-based heart health promotion activities.

16.

Title	Long-term care restructuring in rural Ontario: retrieving community service user and provider narratives
Author(s)	Cloutier-Fisher,-Denise; Joseph,-Alun-E
Journal	Social Science and Medicine
Pub. Date	2000, Apr. v.50 no7/8
Pages	1037-45
Abstract	This paper examines the extensive restructuring of community-based long-term care that was initiated in Ontario, Canada in 1996, and does so with particular reference to longstanding problems of provision in rural communities. Specifically, it draws on a case study focussed on two small rural towns to develop a 'situated understanding' of service-user and service-provider perspectives on service coordination issues and on service cuts, particularly as they affect the ability of elderly people reliant on publicly-funded community services to stay in their homes, to continue to 'age in place'. The general and specific antecedents of long-term care reform are considered prior to the presentation of the case study. General antecedents include the rapid aging of Canada's population and aggressive strategies to reduce government deficits, while specific antecedents flow from a decade of failed attempts to address longstanding issues of service co ordination and from the ideologically-driven, free market stance of the provincial government elected in 1995. The analysis of interviews conducted with 14 community-service users and 17 providers suggests that the managed competition system introduced as the centerpiece of long-term care reform has resulted in increasing diversity and uncertainty on both sides of the service provision equation. Despite continued attempts by rural elderly people and their families to 'cut and paste' support packages, it seems that the restructuring of publicly-funded community services, combined with a substantial re-investment in long-term care facilities, will make some elderly people more vulnerable to institutionalization.

17.

Title	Restructuring public health in Ontario: Implications for heart health promotion
Author(s)	Elliott, SJ; Taylor, SM; Wilson, K; Robinson, K Riley, B; Walker, R
Journal	CANADIAN JOURNAL OF PUBLIC HEALTH-REVUE CANADIENNE DE SANTE PUBLIQUE
Pub. Date	2000, MAR-APR v.91/2
Pages	94-97
Abstract	Cardiovascular disease is the principal cause of death and disease in most western nations.' Community-based heart health promotion is viewed as an effective means of reducing cardiovascular disease risk. Although public health agencies have a central role in the implementation and dissemination of heart health programs,(2) their effectiveness is being challenged by major structural changes to provincial public health systems across Canada. While 9 of Canada's 10 provinces have undergone a devolution of health care decision making to the local level over the past decade or so,(3) there has been little systematic analysis of the effects of this devolution on public health practice and/or the role of a population health perspective in addressing public health challenges.(4) Ontario is the one exception to the apparent national trend toward regionalization of health care.(3) The public health system in Ontario is currently being challenged, however, by major structural changes. The first of these involves the 'municipalization' of funding responsibilities. In January 1997, the Ontario government announced a change in funding from the previous cost-shared arrangement for beards of health to a requirement that boards be 100% municipally funded as of January 1, 1998. At the same time, the province is seeking to retain control through the regulation of public health standards set out in the recently revised "Mandatory Health Programs and Services Guidelines."(5.6) The major guideline change (potentially) affecting heart health staff was the reorientation of the three primary risk factor areas (i.e., nutrition, physical activity and tobacco use prevention) from a perspective of 'Healthy Lifestyles' to 'Chronic Disease Prevention'. At the time of this study in 1997, the second and penultimate draft had been circulated to each public health unit. As part of the Canadian Heart Health Initiative - Ontario Project (CHHIOP), this study used a qualitative approach to address questions of the implications of these major structural changes to Ontario's public health system for heart health promotion. Detailed descriptions of CHHIOP have been published previously.(7-10) The specific questions addressed in this paper are: 1) What are the perceptions of public health staff with respect to the changes in the mandatory guidelines and the implications of these changes for heart health promotion! and, 2) What is the future of public health in Ontario in light of the transfer of costs to municipalities! More specifically, what are the perceived implications for local heart health promotion and for population health-based strategies?

18.

Title	The practice of community development approaches in heart health promotion
Author(s)	Robinson, KL; Elliott, SJ
Journal	HEALTH EDUCATION RESEARCH
Pub. Date	2000, APR v.15/2
Pages	219-231
Abstract	There has been a recent shift in public health policy towards population-based approaches to the reduction of cardiovascular disease. This shift has been accompanied by a re-examination of strategies appropriate to the goal. Often, community development approaches, designed to affect socio-environmental change, are suggested as the most appropriate strategy for affecting community-wide change. Despite the fact that community development approaches have been used by several of the major community-based heart health initiatives, evidence of their use and usefulness remains sparse. This paper presents the findings of a qualitative study of the factors (i.e. community context, facilitators, barriers) affecting the use of community development approaches to heart health promotion in Ontario, Canada. Key informant interviews (n = 30) were conducted with stakeholders representing voluntary agencies, community health providers, boards of education and local coalitions in eight of the 42 health unit areas across Ontario. The qualitative analysis reveals (1) that the use of comprehensive community development approaches is limited and (2) that community agencies typically employ elements of community development approaches (e.g. community organization, community-based), often in combination and adapted to suit local conditions. The resulting landscape of community development approaches is characterized by a continuum of collaborative practices indicating that no one type of community approach is appropriate for all initiatives and in all communities. Therefore, from a programmatic perspective, it may not be realistic to advocate community development as the goal to which all communities should strive.

19.

Title	The policy context for community development practice in public health: A Canadian case study
Author(s)	Poland, B; Boutilier, M; Tobin, S; Badgley, R
Journal	JOURNAL OF PUBLIC HEALTH POLICY
Pub. Date	2000, v.21/1
Pages	5-19
Abstract	The Community Action in Public Health Study explored how public health managers, frontline staff, and community participants interpret, implement and receive policy guidelines urging collaboration with community groups in public health work. In-depth case studies of 6 public health units in Ontario, Canada focussed on several community development projects in 3 program areas (107 interviews). In the absence of formal policy guidelines on community development at provincial or local levels, informal policy predominated. Local senior management frequently set the tone, distinguishing health units in which community development was a basic philosophy underlying a broad spectrum of public health practice from those in which it was seen as only one among many possible strategies. Uncertainty and risk associated with informal policy lead many frontline staff to adopt strategies intended to preserve autonomy in community work, including "seeking forgiveness rather than permission" and maintaining relative "invisibility."

20.

Title	Delivering the 'new' Canadian midwifery: the impact on midwifery of integration into the Ontario health care system
Author(s)	Bourgeault, IL
Journal	SOCIOLOGY OF HEALTH & ILLNESS
Pub. Date	2000, MAR v.22/2
Pages	172-196
Abstract	This paper addresses the impact on midwifery of its recent integration into the provincial health care system in Ontario, Canada. Data are derived from participant-observation, primary and secondary source documents, and key informant interviews. Based on these data, I argue that midwifery has changed throughout the integration process but it has also successfully resisted change. Specifically, the organisation of the midwifery community evolved from an amorphous social movement to a more bureaucratically organised profession. The regulation of midwifery also shifted from direct-regulation by clients to professional self-regulation. The educational model of midwifery also changed from an eclectic apprentice-based approach to a more standardised baccalaureate degree programme. The midwifery model of practice, however, was sustained. Although these changes occurred at the hands of key members of the midwifery community, they were made in response to the structural context of the health care system into which they were attempting to become integrated.

21.

Title	Economic approaches to the third sector: The contributions and limitations of neo-classical analyses.
Author(s)	Nyssens, M
Journal	SOCIOLOGIE DU TRAVAIL
Pub. Date	2000, OCT-DEC v.42/4
Pages	551-565
Abstract	The third sector has intrigued, and still does, economists who have used the neo-classical theory to conduct studies of it. Various approaches in the literature in English are discussed. From a viewpoint initially adopted to explain market phenomena, they try to account for the presence and relative efficiency of non-profit organizations in the service sector. Two major types of approaches are distinguished: a) demand theories (the theory of social efficiency and the theory of organizations) that inquire into the reasons why actors - consumers or public authorities, for example - resort to non-profit organizations; b) supply theories that try to justify recourse to non-profit organizations as a 'mode of productive organization' by raising questions about information, the opportunism of actors and the specific nature of 'collective goods'. The scope of these approaches is assessed; and the limitations and contradictions of an analytical framework stretched far beyond the bounds of market relations (for which it was initially developed) are pointed out.

22.

Title	The third sector: a subject of study for economic sociology.
Author(s)	Laville, JL
Journal	SOCIOLOGIE DU TRAVAIL
Pub. Date	2000 OCT-DEC v.42/4
Pages	531-550
Abstract	This analysis shows that, already in the 19th century, the utopia of the self-regulating market had spawned a political debate about the economy to which many collective initiatives from the civil society, partially relayed by the Welfare State but still existing in a third sector contributed. The 'Civil and Solidarity Based Economy' perspective emphasizes the interactions between this third sector and evolving public policies. The globalization of the economy, the 'tertiarization' of productive activities and long-term socio-demographic trends are reviving associations in this sector. Their future is linked both to this process and to changes in forms of public regulation. Other forms of regulation have cropped up alongside state oversight, the form that prevailed till the 1970s. The respective weights of these forms vary depending on both the type of welfare state and the configuration both of networks of initiatives and of types of international exchanges.

23.

Title	Mission statements in Canadian not-for-profit hospitals: does process matter?
Author(s)	Bart CK, Tabone JC
Journal	Health Care Manage Rev
Pub. Date	2000, Spring, v.25/2
Pages	45-63
Abstract	Mission statements abound in health care organizations. And much is written on what they should contain. But, the process of creating and implementing mission statements in health care organizations has received virtually no attention in the literature. This article presents findings from a research study that sought to determine whether or not a relationship existed between selected mission process characteristics and various measures of a hospital's performance.

24.

Title	The Fort McMurray Demonstration Project in Social Marketing: Theory, design, and evaluation
Author(s)	Guidotti, TL; Ford, L; Wheeler, M
Journal	AMERICAN JOURNAL OF PREVENTIVE MEDICINE
Pub. Date	2000, FEB v.18/2
Pages	163-169
Abstract	Context: The Fort McMurray Demonstration Project in Social Marketing is a multifaceted program that applies the techniques of social marketing to health and safety. This paper describes the origins of the project and the principles on which it was based. Venue: Fort McMurray, in the province of Alberta, Canada, was selected because the community had several community initiatives already underway and the project had the opportunity to demonstrate "value added." Concept: The project is distinguished from others by a model that attempts to achieve mutually reinforcing effects from social marketing in the community as a whole and from workplace safety promotion in particular. Design: Specific interventions sponsored by the project include a media campaign on cable television, public activities in local schools, a community safety audit, and media appearance by a mascot that provides visual identity to the project, a dinosaur named "Safetysaurus." The project integrated its activities with other community initiatives. Main Outcome Measures: The evaluation component emphasizes outcome measures. A final evaluation based on injury rates and attitudinal surveys is underway. Results: Baseline data from the first round of surveys have been compiled and published. In 1995, Fort McMurray became the first city in North America to be given membership in the World Health Organization's Safe Community Network.

25.

Title	The use of research in local health service agencies
Author(s)	Anderson,-Malcolm; Cosby,-Jarold; Swan,-Bill
Journal	Social-Science-and-Medicine
Pub. Date	1999, Oct. v.49/8
Pages	1007-19
Abstract	A critical and often overlooked component of the use and transfer of research in the health care system is the local health and social service delivery agency. There is also very little understanding of the extent to which local community-based agencies conduct research internally to improve their operational capacity. More than ever, these local service organizations require research to guide activity in a rapidly changing health care environment which is characterized by diminishing health and social service budgets, de-institutionalization and concomitant increases and metamorphoses in service demands. This study interviewed 25 executive directors and held a focus group with a group of other directors to examine the use and transfer of research in these organizations. A number of central issues were identified by the directors that affect the contribution of research to the delivery of their programs and services. A conceptual model for developing 'locally-based research transfer was subsequently outlined that could serve as the basis for enhanced research use and research transfer in other local area contexts.

26.

Title	Health care reform and reform for health: creating a health system for communities in the 21st century
Author(s)	Hancock,-Trevor
Journal	Futures (London, England).
Pub. Date	1999 June v.31/5
Pages	417-36
Abstract	If we are to improve the health of the population and reduce the inequalities in health that plague our communities and our planet, we will have to give greater attention to the determinants of health. The reform of the health care system, necessary though it is, will never be sufficient; we need to reform our whole society and in particular to focus on human rather than economic development. At the community level we need to create healthy communities that are "health-creating systems" of environmental, social and human development, as well as health care systems that focus first on improving and maintaining health. Such a "bottom-down" health care system would see the hospital become once again the place of last resort (but still a potentially important partner in creating healthier communities) and would focus instead on how to provide health promotion and health care from the household level up.

27.

Title	Understanding the use of a community-based drive-home service after alcohol consumption among young adults
Author(s)	Lavoie,-Michel; Godin,-Gaston; Valois,-Pierre
Journal	Journal of Community Health.
Pub. Date	1999, June v.24/3
Pages	171-86
Abstract	To know and understand the intention of young adults to use, during the Christmas and New Year's period, the community drive-home service after drinking alcohol, that is, to phone for oneself when they are the driver or when they are the passenger to suggest to a friend who is the driver to phone for the service. This study was conducted in the Province of Quebec, Canada, among a representative sample of 544 young adults aged 18 to 24 years. Self-administered questionnaires were completed by mail. Young adults showed a very good knowledge of the drive home service and had a very positive attitude toward its use. Among those who reported having experienced drinking too much alcohol during the Christmas and New Year's period, 17 percent had phoned when they were the driver and 36 percent had, when they were a pass.nger, suggested to a friend who was the driver to phone the community drive-home service. Nonetheless, more than half of them intended to use or to recommend its use to a friend in the future. Several factors identified in this study might be useful for increasing this drive-home service and therefore, contribute to lowering the risk of injury related to alcohol-impaired driving among young adults.

28.

Title	Effectiveness of community-directed diabetes prevention and control in a rural aboriginal population in British Columbia, Canada
Author(s)	Daniel,-Mark; Green,-Lawrence-W; Marion,-Stephen-A
Journal	Social Science and Medicine
Pub. Date	1999 Mar. v.48/6
Pages	815-832
Abstract	This report presents the process and summative evaluation results from a community-based diabetes prevention and control project implemented in response to the increasing prevalence and impact of non-insulin-dependent diabetes mellitus (NIDDM) in the Canadian Aboriginal population. The 24-month project targeted the registered Indian population in British Columbia's rural Okanagan region. A participatory approach was used to plan strategies by which diabetes could be addressed in ways acceptable and meaningful to the intervention community. The strategies emphasized a combination of changing behaviours and changing environments. The project was quasi-experimental. A single intervention community was matched to two comparison communities. Workers in the intervention community conducted interviews of individuals with or at risk for diabetes during a seven-month pre-intervention phase (n = 59). Qualitative analyses were conducted to yield strategies for intervention. Implementation began in the eighth month of the project. Trend measurements of diabetes risk factors were obtained for "high-risk" cohorts (persons with or at familial risk for NIDDM) (n = 105). Cohorts were tracked over a 1 6-month intervention phase, with measurements at baseline, the midpoint and completion of the study. Cross-sectional population surveys of diabetes risk factors were conducted at baseline and the end of the intervention phase (n = 295). Surveys of community systems were conducted three times. The project yielded few changes in quantifiable outcomes. Activation of the intervention community was insufficient to enable individual and collective change through dissemination of quality interventions for diabetes prevention and control. Theory and previous research were not sufficiently integrated with information from pre-intervention interviews. Interacting with these limitations were the short planning and intervention phases, just 8 and 16 months, respectively. The level of penetration of the interventions mounted was too limited to be effective. Attention to process is warranted and to the feasibility of achieving effects within 24 months.

29.

Title	Home is where the governing is: social capital and regional health governance
Author(s)	Veenstra, G; Lomas, J
Journal	HEALTH & PLACE
Pub. Date	1999, MAR v.5/1
Pages	1-12
Abstract	The relationship between the civic nature of a community and effective political governance by regional health boards in Canada is explored. A model is proposed that identifies components of social capital such as trust, commitment and identity, associationalism, civic participation and collaborative problem-solving. These concepts are then theoretically linked to effective governance, in particular to reflection of health needs, policy implementation. population health, fiscal responsibility and administrative efficiency. The generalizability of this model is discussed, as are current research directions and policy implications for governments. The conclusion is that governments might want to incorporate a dual perspective encompassing both the political institutions and the community structure.

30.

Title	Guthrie House: a rural community organizing for wellness
Author(s)	Halseth, G; Williams, A
Journal	HEALTH & PLACE
Pub. Date	1999, MAR v.5/1
Pages	27-44
Abstract	This paper is interested in the issue of community participation and empowerment in health care provision and decision-making. In Canada, the present scope for public involvement in planning or managing the state's health and social services system is limited. This poses a particular problem for rural communities - places where the provision of health care services has historically been limited when compared to urban locations. These rural communities are now facing a double burden as public policy moves increasingly towards a retrenchment of the welfare state. This paper examines one rural community's response to this double burden. The village of Elgin in rural Ontario recently established Guthrie House, a community-based resource center for health and wellness services. Community participation in this case involved a level of control whereby local citizens together defined the health and social care services that they saw as best meeting the needs of their community. This form of community participation is considerably different from the forms of public involvement in the established medical system and represents a critical link to 'empowering' the local community as partners in health care. Through an examination of Guthrie House, the payer presents a review of some critical 'characteristics' which mark successful community self-help organizations and concludes with a discussion of the policy implications for greater community participation. It is argued that such community participation in health care is a policy option which government should be paying particular attention to in these times of fiscal constraint, increasing health care needs and increasing consumer dissatisfaction with government service provision mechanisms.

31.

Title	Rationing care in the community: Engaging citizens in health care decision making
Author(s)	Redden, CJ
Journal	JOURNAL OF HEALTH POLITICS POLICY AND LAW
Pub. Date	1999, DEC v.24/6
Pages	1363-1389
Abstract	This article examines the theoretical and practical logics of community engagement exercises in health care rationing. To evaluate such exercises in Canada, it is necessary to compare suspected rationing exercises (such as those in Nova Scotia and Saskatchewan) with clear examples of rationing. The Oregon Medicaid reform process is considered an important example of transparent and community-level rationing from which Canadian executive-driven governments can learn a few valuable lessons. While the Oregon experiment seems to have been a (qualified) success, in the Canadian context, formal citizen participation in decision making might be incompatible with social rights and present an incongruous and antagonistic pairing of executive and popular sources of authority.

32.

Title	Policy trade-offs in "home care": the Ontario example
Author(s)	Baranek, PM; Deber, R; Williams, AP
Journal	CANADIAN PUBLIC ADMINISTRATION-ADMINISTRATION PUBLIQUE DU CANADA
Pub. Date	1999, SPR v.42/1
Pages	69-92
Abstract	As Canada enters the twenty-first century, its highly prized program, medicare, is undergoing radical transformation. With technological change and the restructuring of health systems, the locus of care is shifting from institutions to the home. As a result, care that was formerly publicly financed under the Canada Health Act is technically becoming de-insured. This paper analyses the reform of community-based long-term care services in Ontario from 1985 to the present. During this period, three different parties, the Liberals, the NDP and the Progressive Conservatives, in turn, formed the government. Four different models were put forward before the current model was adopted by the current pc government. Each of these models is analysed with respect to design decisions that must be made in the policy dimensions of financing, delivery and allocation and evaluated in terms of equity, liberty, security and efficiency. Underlying the debate in Ontario was a fundamental disagreement about the role of government, reflected in views about the responsibilities of individuals and their families, and the appropriate place of for-profit organizations within a publicly funded system. The reform of this sector has significance that goes beyond its boundaries, with wider implications and warnings for health care in general.

33.

Title	The impact of a community-based heart disease prevention program in a low-income, inner-city neighborhood
Author(s)	O'Loughlin, JL; Paradis, G; Gray-Donald, K; Renaud, L
Journal	AMERICAN JOURNAL OF PUBLIC HEALTH
Pub. Date	1999, DEC v.89/12
Pages	1819-1826
Abstract	Objectives. This study evaluated the impact of a 4-year, community-based cardiovascular disease prevention program among adults aged 18 to 65 years living in St-Henri, a low-income, inner-city neighborhood in Montreal, Quebec. Methods. Awareness of and participation in the program were monitored in 3 independent sample telephone surveys. Self-reported behaviors were compared in St-Henri and a nearby comparison community before and after program implementation in both a 3-year repeat independent sample survey and a 5-year longitudinal cohort telephone survey. Results. Awareness of the program reached 37.4%, but participation was low (2%-3%). There were no secular declines in smoking or high-fat diet; physical inactivity increased in both communities. There were no statistically significant program effects detected in the independent sample surveys, although physical inactivity increased more in the comparison community than in St-Henri. In the longitudinal cohort sample, there was a small, statistically significant increase favoring St-Henri in frequency of cholesterol checkups. Conclusions. Despite careful adaptation of the program to the local social context, there were few community-wide program effects. However, several component interventions showed promise in terms of community penetration and impact.

34.

Title	Outcomes research and community health information systems
Author(s)	Slater, CH
Journal	JOURNAL OF MEDICAL SYSTEMS
Pub. Date	1999, AUG v.23/4
Pages	335-347
Abstract	The developments in outcomes research and community health information systems are pursuing essentially parallel courses in this country, and yet integrating the lessons from each other could yield more informed health policy decisions. This article provides the linkage between these two developing fields, discusses indicators of community health, describes several approximations to an outcomes-based community health information system in this country, and specifies a model (POPULIS) of such a system from Canada. Although POPULIS can serve as a prototype for health policy decision making, the outcomes-based community health information system, which can be constructed in this country, is constrained by the pluralistic system of health care we have and the lack of any centralized planning about health.

35.

Title	"Nurses as health evangelists"?: The evolution of public health nursing in Canada, 1918-1939
Author(s)	Duncan, SM; Leipert, BD; Mill, JE
Journal	ADVANCES IN NURSING SCIENCE
Pub. Date	1999, SEP v.22/1
Pages	40-51
Abstract	Public health nurses provided leadership for the advancement of public health in Canada in the early decades of this century, although leadership by nurses is not celebrated in public health history. The historical period (1918-1939) selected for this inquiry is one in which public health nurses created a legacy of achievements in public health nursing education, practice, and the organization of community health services within the most challenging of social, economic, and political contexts. The practice of public health nursing in Canada during the interwar years included strategies that were then and still are integral to the discipline-those of forming connections with the community, providing leadership in the public health movement, and facilitating community organization. It is vital to understand the significance of these origins of public health nursing as forces in the present context of practice threaten to alter fundamentally the nature of public health nursing's connection with the community. The purpose of this article is to highlight aspects of this historical legacy so that its influence can be more fully understood and strengthened in current health system transitions.

36.

Title	Closing rural hospitals in Saskatchewan: on the road to wellness?
Author(s)	James, AM
Journal	SOCIAL SCIENCE & MEDICINE
Pub. Date	1999, OCT v.49/8
Pages	1021-1034
Abstract	Rising health care costs at a time of economic stagnation, federal cutbacks to Medicare, and an obsession with budget deficits at all levels of government have contributed to a sense of urgency to reform the Canadian health care system. Accompanying these economic and political motivations for reform, has been a shift in our understanding of health and well-being that lays less emphasis on the institutionalization and medicalization of health care. As part of its wellness approach to health, the Saskatchewan government in 1992 announced the closure and conversion of 52 small rural hospitals to wellness centres as part of a shift from institutional care to community based care. While the health costs and benefits of this shift are contested, the paradox is that closing rural hospitals may have unrealized health and social costs because of the psychological and community importance of hospitals to the meaning of place. This paper begins with a review of the meaning and importance of local institutions for communities. It is clear from this starting point that the debate about the economic and health benefits and costs of rural hospital closures is a limited basis for understanding hospital closures. Finally, the history of Saskatchewan hospitals and a narrative of the recent closures of rural hospitals drawn from a sampling of provincial newspapers and oral discussions highlights the need to understand the hospital closure in terms of its impact on health irrespective of the medical impacts.

37.

Title	Long-term care goes to market: Managed competition and Ontario's reform of community-based services
Author(s)	Williams, AP; Barnsley, J; Leggat, S; Deber, R; Baranek, P
Journal	CANADIAN JOURNAL ON AGING-REVUE CANADIENNE DU VIEILLISSEMENT
Pub. Date	1999, SUM v.18/2
Pages	125-153
Abstract	A shift in emphasis from institutions to community poses important challenges for providers and policy makers, key among them being the challenge of providing a sufficient volume of high quality community-based services to meet consumer needs. This challenge is particularly evident in community-based long-term care (LTC) due to the complexity and diversity of the field, the vulnerability of the population served, and the current wave of demand for services generated by hospital downsizing. The most recent reform of long-term care in Ontario is of particular interest in this context because, as suggested by the provincial government's maxim "highest quality, best price," it promises cost-efficiency while maintaining or improving quality. To do this it employs a "managed competition" model in which for-profit and not-for-profit providers compete for service contracts under the auspices of local Community Care Access Centres (CCACs) run by volunteer boards. In this paper we draw on the comments of senior government officials and representatives of provider organizations, as well as published documents, to highlight issues and problems posed by the province's latest reform. We argue that, particularly under conditions of capped budgets and increasing demands, the managed competition process may result in the subordination of service quality and consumer choice to pressures for cost-containment.

38.

Title	Pilot study of a visitor volunteer programme for community elderly people receiving home health care
Author(s)	MacIntyre, I; Corradetti, P; Roberts, J; Browne, G; Watt, S; Lane, A
Journal	HEALTH & SOCIAL CARE IN THE COMMUNITY
Pub. Date	1999, MAY v.7/3
Pages	225-228
Abstract	There is a need to evaluate community support programmes for elderly people. In this randomized control trial (RCT), we determined the effectiveness of 'friendly visitors' in a volunteer programme of a visiting nurses organization in Southern Ontario, Canada. The Volunteer Friendly Visitor Programme was developed to support elderly people receiving homemaking and nursing care in the community. Volunteers are screened, trained, interviewed and matched to homebound elderly clients for general interest, visit expectations and personality. Volunteers spend three to four hours on average per week with clients socializing in mutually agreed-upon ways. The nursing staff identified clients who were lonely for this additional support. These newly-referred clients were randomly allocated to receive a friendly visitor or not for six weeks. Those receiving the volunteer visitor improved in life satisfaction and two social support measures: worth and social integration. Thus, the addition of volunteer visitors to planned homemaking and nursing care made a difference for elderly in the community.

39.

Title	The use of senior volunteers in the care of discharged geriatric patients
Author(s)	Dulka, IM; Yaffe, MJ; Goldin, B; Rowe, WS
Journal	JOURNAL OF SOCIOLOGY AND SOCIAL WELFARE
Pub. Date	1999, MAR v.26/1
Pages	69-85
Abstract	This article reports on a project that utilized senior volunteers in the role of health advocates for geriatric patients discharged from a hospital. The project was evaluated to determine if healthy and active seniors could make a contribution to the health and social welfare of such discharged elderly persons. The study was conducted in Montreal, Canada and funded by a federal grant from Health Canada. The research collaborators came from a 414-bed secondary cave university-affiliated community hospital, a community social service agency with a mandate to respond to Me needs of its frail elderly constituents, and a university-based research centre that works with health professionals in various settings to develop and evaluate service programs addressing the needs of disadvantaged families and individuals.

40.

Title	Effectiveness of community-directed diabetes prevention and control in a rural Aboriginal population in British Columbia, Canada
Author(s)	Daniel, M; Green, LW; Marion, SA; Gamble, D; Herbert, CP; Hertzman, C; Sheps, SB
Journal	SOCIAL SCIENCE & MEDICINE
Pub. Date	1999, MAR v.48/6
Pages	815-832
Abstract	This report presents the process and summative evaluation results from a community-based diabetes prevention and control project implemented in response to the increasing prevalence and impact of non-insulin-dependent diabetes mellitus (NIDDM) in the Canadian Aboriginal population. The 24-month project targeted the registered Indian population in British Columbia's rural Okanagan region. A participatory approach was used to plan strategies by which diabetes could be addressed in ways acceptable and meaningful to the intervention community. The strategies emphasised a combination of changing behaviours and changing environments. The project was quasi-experimental. A single intervention community was matched to two comparison communities. Workers in the intervention community conducted interviews of individuals with or at risk for diabetes during a seven-month pre-intervention phase (n = 59). Qualitative analyses were conducted to yield strategies for intervention. Implementation began in the eighth month of the project. Trend measurements of diabetes risk factors were obtained for 'high-risk' cohorts (persons with or at familial risk for NIDDM) (n = 105). Cohorts were tracked over a 16-month intervention phase, with measurements at baseline, the midpoint and completion of the study. Cross-sectional population surveys of diabetes risk factors were conducted at baseline and the end of the intervention phase (n = 295). Surveys of community systems were conducted three times. The project yielded few changes in quantifiable outcomes. Activation of the intervention community was insufficient to enable individual and collective change through dissemination of quality interventions for diabetes prevention and control. Theory and previous research were not sufficiently integrated with information from pre-intervention interviews. Interacting with these limitations were the short planning and intervention phases, just 8 and 16 months, respectively. The level of penetration of the interventions mounted was too limited to be effective. Attention to process is warranted and to the feasibility of achieving effects within 24 months.

41.

Title	Valuation of unpaid help by seniors in Canada: An empirical analysis
Author(s)	Robb, R; Denton, M; Gafni, A; Joshi, A; Lian, J; Rosenthal, C; Willison, D
Journal	CANADIAN JOURNAL ON AGING-REVUE CANADIENNE DU VIEILLISSEMENT
Pub. Date	1999, WIN v.18/4
Pages	430-446
Abstract	The demographic shift towards an older population in Canada has led to concerns about the increased share of society's resources required to provide health care, social assistance, public pensions, housing, etc. for this group. Preoccupation with this problem, however, has obscured the fact that seniors actively contribute to society in many ways, not the least of which is the provision of substantial amounts of unpaid time contributions of various sorts. Using data from the 1992 General Social Survey on Time Use (cycle 7), this paper estimates the amount and market value (at replacement cost) of unpaid help -both informal help to others and formal help to organizations - of individuals age 55 and over. Travel time in connection with unpaid help is also analysed. We find that participation rates and average hours are higher in the informal help sector relative to the formal sector both by age and by gender. The estimates also show that the market value of these contributions is substantial, and that seniors contribute a disproportionate share of the value of unpaid help contributed by all individuals over the age of 25.

42.

Title	Lessons in community development: attempting to create a community wellness centre
Author(s)	Kulig,-Judith-C.; Waldner,-Magda
Journal	Journal-of-the-Community-Development-Society
Pub. Date	1999 v.30/1
Pages	29-47
Abstract	Describes failed attempt to develop a community wellness center (CWC) in rural Greenstown, southern Alberta; examines location selection, power, lack of leadership, differences in interpretation, role of Regional Health Authority (RHA), citizen participation, and other issues.

43.

Title	Total quality management in non-profit secondary health care
Author(s)	Trenchard, PM
Journal	TOTAL QUALITY MANAGEMENT
Pub. Date	1999 SEP v.10/7
Pages	979-986
Abstract	The management of non-profit secondary health care is significantly influenced by the cost/price signals of key components within the casemix process. The total quality management (TQM) of health care requires an understanding of the nature of these costs. This paper demonstrates that the historic view of the allocation of costs in the case of joint products, such as those in transfusion manufacturing, is that they can only be solved in an arbitrary manner. In contrast, this paper describes a quality-based rationale for the allocation of joint costs to plasma, red cells and platelets, as routinely manufactured from whole blood. The key element is first to trace joint-process costs to product specification elements, rather than directly to products. By this means, final product costs become valid for cost-benefit analysis. This should significantly affect many cost-benefit decisions in the practice of transfusion medicine. It should also retrieve the current probable misallocation of secondary health care resources, estimated at approximately pound 200 000 000 per annum for Western Europe on the basis of historically determined cost models. Quality-driven blood product costing is shown to be central to the achievement of the TQM of secondary health care.

44.

Title	Problems in search of solutions: health and Canadian aboriginals
Author(s)	Newbold,-K.-Bruce
Journal	Journal-of-Community-Health
Pub. Date	1998, Feb v.23/1
Pages	59-73
Abstract	The purpose of this paper is to explore the health status of Canadian Aboriginals, along with their perceived community health problems and proposed solutions to these issues. Data are drawn from the 1991 Aboriginal Peoples Survey (APS), which is a weighted random sample of the Aboriginal population. Comparisons were made with respect to group identity (North American Indian, Metis and Inuit) and geographic location (reserve, urban, rural and North) and across a series of health status and health care use indicators. Analysis reveals that geographic location, as compared with Aboriginal identity, appears to have a large impact with respect to health status and use of physician services. On-reserve Aboriginals, for example, reported a lower likelihood of having seen a physician and were more likely to rank their health as fair or poor. Location also influenced perceived community health problems and solutions. Self-identified problems included drugs, cancer and arthritis, while corresponding solutions included education, counseling and service access. Although the problems and solutions were relatively consistent across space, they too varied in their importance. In general, the results tend to reinforce the determinants of health framework, suggesting that the provision of health services is insufficient to remove health disparities on its own. Instead, broader social-welfare provisions must be considered.

45.

Title	Substituting home care for hospitalization: the role of a quick response service for the elderly
Author(s)	Brazil,-Kevin; Bolton,-Cindy; Ulrichsen,-Doreen
Journal	Journal of Community Health
Pub. Date	1998 Feb. v.23/1
Pages	29-43
Abstract	The purpose of the present study was to examine the role of a rapid access home-based service as a means for the elderly to avoid admission to an acute-care hospital. The setting for the study included emergency departments in three acute care hospitals and a home care program in a mid-size Canadian city. Multiple sources of information were obtained to evaluate the service. Hospital emergency department records and home care records were reviewed. Patients who participated in the service (n = 96) and physicians and nurses (n = 119) who had involvement with the service were surveyed appraising the service in terms of relevance, access, quality and coordination. Study results revealed that elderly women with multiple health problems who lived alone were the most frequent users of the service. The majority of the patients admitted to the service presented with problems of a functional nature that were the result of a fall or mobility problems. The results indicated that the service did avert hospital admissions and facilitated a process by which patients could avoid the intermediate step of hospitalization before placed in a higher level of care or returning to previous levels of functioning. Economic analysis indicated that the value of the service stemmed from the benefits to patients and caregivers rather than from cost savings offered to acute care hospitals.

46.

Title	Restructuring health services delivery research: a community-based model
Author(s)	Sellors, JW; Mitchell, C
Journal	CLINICAL AND INVESTIGATIVE MEDICINE-MEDECINE CLINIQUE ET EXPERIMENTALE
Pub. Date	1998; AUG-OCT v.21/4-5
Pages	203-208
Abstract	As management of acute illness shifts to the community from tertiary care centres, there is a need for community-based research into the delivery of health services. One author is the coordinator of a health services delivery research unit located in a community health centre as well as the director of research in the Department of Family Medicine at McMaster University. The other author is a member of the administration of the sponsoring institution. The research unit, created in 1994, has close links with the sponsoring hospital, a research centre and the faculty of health sciences at a nearby university. Its staff has grown from 2 to 12 members, mainly as a result of grant support. Its aim is to improve the delivery of community-based health services, and to this end it conducts research in collaboration with programs at the health centre, stakeholder groups, communities and institutions. Research projects have been undertaken in clinical guidelines, women's health, mature adults' health, medication use and new technologies for screening. As an example, concern about chlamydial infections in women in the community led to research into burden of illness, diagnosis, screening methods, test technologies, validation of guidelines and provider behaviour. In the future, funding will be a major concern. The authors contend that more funding from such agencies as the Medical Research Council of Canada should flow to community-based research.

47.

Title	Is community-based treatment an add-on or a substitution for hospital treatment of alcoholism? Some evidence from Canada
Author(s)	Adrian, M; Ferguson, B; Dini, C
Journal	MEDICAL CARE
Pub. Date	1998, SEP v.36/9
Pages	1419-1429
Abstract	OBJECTIVES. This study determined whether the development of community treatment of alcohol problems acted as an add-on or a substitution for the utilization of inpatient hospital services in Ontario. METHODS. Complex modelling and graphic analyses using econometric multiple regression techniques were performed on data for the 48 counties of Ontario (Canada) for the period 1972 to 1988, combining both cross-sectional and time series analysis. RESULTS. After controlling for differences in alcohol consumption in health care characteristics such as the supply of physicians or hospital occupancy rates, and in socioeconomic characteristics of the population, when community treatment became available, hospital utilization for the treatment of alcohol problems decreased and community services were substituting for hospital treatment. In addition, nonresidential services had an overall greater importance in producing this effect (elasticities at the mean of -0.11 to -0.14 depending on the region) than community-based residential treatment. The effect was larger in the southern than in the northern counties of Ontario. Testing of the modelling techniques showed statistically significant and satisfactory modelling of the forces at work. CONCLUSIONS. Where community-based treatment was available, it was used in preference to inpatient hospital treatment; however, there may be a slightly more complex relationship present in the southern urban counties (which contain the larger metropolitan areas) than in the northern and southern rural counties.

48.

Title	Community service providers as literacy facilitators: A pilot project
Author(s)	Hayden, R; Sanders, M
Journal	ALBERTA JOURNAL OF EDUCATIONAL RESEARCH
Pub. Date	1998, SUM v.44/2
Pages	135-148
Abstract	A pilot project was conducted with 20 community service providers that included health, social, and other professional workers from an inner-city area in one of Canada's capital cities. The goals of the project were (a) to explore a range of community service providers' perspectives on literacy; (b) to determine if six hours of training in family literacy development strategies modified community service providers' understanding of literacy learning; and (c) to examine how community service providers, as a result of the training, incorporated literacy events for the families they serve in their professional practice. Participants were involved in two three-hour workshops directed to literacy acquisition in general and family literacy practices in particular Data were collected through pre- and post-survey questionnaires, individual interviews, and information collected during the workshops. Results indicate that participants demonstrated a shift in attitudes from skills achievement to sociocultural perspectives on literacy acquisition. The community service providers also attended to and included literacy events more frequently in their own professional practices after workshop participation.

49.

Title	The changing environment of community health practice and education: Perceptions of staff nurses, administrators, and educators
Author(s)	Chalmers, KI; Bramadat, IJ; Andrusyszyn, MA
Journal	JOURNAL OF NURSING EDUCATION
Pub. Date	1998, MAR v.37/3
Pages	109-117
Abstract	Historically, baccalaureate nursing programs in Canada have prepared graduates to practice in the community. Two recent trends-the move to prepare all registered nurses in degree programs and the changing climate in which community nursing is practiced-made it timely to explore the educational preparation required for community health practice. This article reports on one part of the study, i.e., on findings that explicate the nature of community health nursing practice in a western Canadian province, as it has changed during the past decade, as it is currently practiced, and as it is expected to develop in the future. What, in other words, is the nature of the community practice for which nursing students should be prepared? An action research design guided the study. Participants were recruited from all major urban, rural, and northern settings in which baccalaureate nurses practice throughout the province. The perspective of relevant people was considered important, i.e., nurses practicing in the community, administrators, and educators of future community nurses. One hundred eighteen (118) participants were interviewed in 27 focus groups. Data were tape recorded, transcribed, and analyzed for content. Among the themes identified were those that captured changes community health nurses experienced in their nursing practice. Nurses also described how they thought practice would evolve in the years to come. These themes are discussed within a primary health care framework in which nurses can be expected to play a more active role in shaping community health nursing practice.

50.

Title	The beneficial effects of volunteering for older volunteers and the people they serve: A meta-analysis
Author(s)	Wheeler, JA; Gorey, KM; Greenblatt, B
Journal	INTERNATIONAL JOURNAL OF AGING & HUMAN DEVELOPMENT
Pub. Date	1998, v.47/1
Pages	69-79
Abstract	The current political-economic climate, which is generally supportive of both private and public sector down-sizing, increasingly demands that human service workers assess, engage, and creatively use consumer strengths and resources. This meta-analysis of thirty-seven independent studies provided the means of inferring not only that elder volunteers' sense of well-being seemed to be significantly bolstered through volunteering, but also that such relatively healthy older people represent a significant adjunct resource for meeting some of the service needs of more vulnerable elders, as well as those of other similarly vulnerable groups such as disabled children. Averaging across studies, 85 percent of the "clients" who received service from an older volunteer (e.g., peer-counseling of nursing home residents) scored better on dependent measures (e.g., diminished depression) than the average person in comparison conditions did (U-3 = .847 [Cohen, 1988], combined p <.001). The policy implications of such beneficial effects among both older volunteers and the people they serve are discussed.

51.

Title	Osteoporosis and related diseases: Voluntary organizations
Author(s)	Galsworthy, TD
Journal	DRUG INFORMATION ASSOCIATION
Pub. Date	1998, OCT-DEC v.32/4
Pages	991-996
Abstract	This paper highlights the work of four nonprofit, volunteer osteoporosis educational foundations: the United Stares National Osteoporosis Foundation, the Pager Foundation for Paget's Disease of Bone and Related Disorders, the European Foundation for Osteoporosis and Bone Disease, and the Osteoporosis Society of Canada. All facilitate education across the patient, medical, scientific, general public, and political communities, in order to promote behavioral change in all aspects of disease prevention and management.

52.

Title	Canadian non-profits in crisis: The need for reform
Author(s)	Miller, C
Journal	SOCIAL POLICY & ADMINISTRATION
Pub. Date	1998 DEC v.32/4
Pages	401-419
Abstract	This paper examines recent changes in the relationship between the Canadian state, at both federal and provincial levels, and those non-profit organizations concerned with social welfare. The 1995 federal budget marked a turning point for Canadian non-profit organizations as the federal transfer payments to the provinces were simultaneously restructured and reduced. This, in turn, meant that provincial funds flowing to non-profit organizations would also be cut, or terminated, and restructured as service contracts continued to replace grants. This followed a review of government funding to non-profit agencies initialed the previous year and came on top of a growing critique Of non-profits as unaccountable, unrepresentative, professionalized, "special-interest" groups, who used public funds largely to sustain themselves, and pursued causes that should not be subsidized by government. tit the same lime non-profit organizations were increasingly expected to provide care serial welfare services not only on the basis of "more for less" but also through charging for their services and increased corporate and individual fund-raising. All of these events look place in the context of the election to government, in 1993, of the Liberal Party, that had previously been strongly identified with the advance of a Canadian social agenda but now chose to adopt its conservative predecessor's deficit reduction strategy through public expenditure cuts. For many Canadian commentators, such events have thrown non-profit organizations into crisis and during the past two years there have been attempts to bring together the diverse interests within the sector and build a stronger sense of identity and voice. However, there is also a strong argument to suggest that the vulnerability of such non-profit organizations has resulted, in part, from their over-dependence on government during the previous twenty-five years and the absence of a strong popular base.

53.

Title	Community Health Centers in Canada
Author(s)	Albrecht, D
Journal	International Journal of Health Care Qua. Assur.
Pub. Date	1998, v.11
Pages	5-10
Abstract	N/A

54.

Title	The Canada-international scientific exchange program - A medical model for international research, collaboration, and service
Author(s)	Noyek, AM
Journal	ANNALS OF OTOLOGY RHINOLOGY AND LARYNGOLOGY
Pub. Date	1997, OCT v.106/10
Pages	5-21
Abstract	The Canada-International Scientific Exchange Program (CISEPO) has as its primary objectives to enrich academic medicine and health care in Canada and internationally, and to contribute to peace-building in the Middle East. CISEPO's results are obtained through scientific exchanges, joint research, and clinical programs among Canadian and international scientists and physicians. During the past decade, the relationship between Canadian and international scientists has flourished. CISEPO is a nonprofit, charitable program. Grants and foundation benefactions are applied as seeding for peer-reviewed research, industrial sponsorships, and self-funding clinical and research fellowships. Core funding is provided by the Saul A. Silverman Family Foundation. CISEPO was initiated in 1984 by the Department of Otolaryngology at Mount Sinai Hospital, University of Toronto, Canada, as a formalized, interactive, scientific program between Canada and Israel. Building on its success, CISEPO undertook to broaden its international associations and to expand its partnerships. Currently, CISEPO's programs involve Canadian and other international physicians, scientists, and health care professionals from more than 10 countries in the Middle East, Western Europe, South-East Asia, North America, Eastern Europe, South America, and Australasia. Canadian involvement in CISEPO, in addition to Mount Sinai Hospital and the University of Toronto, includes the Sir Mortimer B. Davis-Jewish General Hospital and McGill University in Montreal, the Baycrest Centre for Geriatric Care in Toronto, McMaster University in Hamilton, and the Royal College of Physicians and Surgeons of Canada. Since its inception, CISEPO's medical and research contributions have included more than 25 textbook chapters, 250 peer-reviewed publications, 500 general publications, and 250 invited lectures and visiting professorships. The productivity of CISEPO's fellows and the success of its internationalism are exemplified by the contributions to and publication of this manual.

55.

Title	The Disabled Women's Network in Canada
Author(s)	Paltiel, FL
Journal	SEXUALITY AND DISABILITY
Pub. Date	1997, SPR v.15/1
Pages	47-50
Abstract	This paper will describe the Disabled Women's Network (DAWN) in Canada, its origins, its significance, and its effective contributions to public awareness and social policy. DAWN was conceived as a result of the realization that the disabled community and its advocates lacked gender awareness or sensitivity, while the women's movement had a blind spot regarding women with disabilities. The paper will consider the topic against the background of disability statistics, the health care system in Canada and from a perspective of needs, risks and tasks of women in general and women with disabilities in particular.

56.

Title	Devolving authority for health care in Canada's provinces .4. Emerging issues and prospects
Author(s)	Lomas, J
Journal	CANADIAN MEDICAL ASSOCIATION JOURNAL
Pub. Date	1997, MAR 15 v.156/6
Pages	817-823
Abstract	DEVOLUTION OF AUTHORITY FOR HEALTH CARE is evaluated in the context of 3 objectives of provincial governments - community empowerment to garner new allies for health care restructuring, service integration to create a true ''system'' and conflict containment as spending is cut. Devolved authorities cannot pursue each of these objectives with equal vigour because they must balance the competing pressures from their provincial government, their providers and their local citizens. Each devolved authority accommodates these pressures in its own way, through different trade-offs. Appointed board members are generally well intentioned in representing the interests of their entire community but are unlikely to overcome formidable barriers to community empowerment in health care. Unless future board elections attract large and representative voter turnouts, they may fragment board members' accountability (by making them more accountable to multiple interest groups) rather than solidify it (by making them more accountable to the community). Although boards have integrated and rationalized parts of the institutional sector, integration of the community sector is hampered by structural constraints such as the lack of budgetary authority for a broader scope of services, including physicians' fees and drugs. Devolved authorities will deflect blame from provincial governments and contain conflict only while they believe that there is still slack in the system and that efficiency can be improved. When boards no longer perceive this, they are likely to add their voices to local discontent with fiscal retrenchment. Continuing evaluation and periodic meetings of authorities to share experiences and encourage cross-jurisdictional policy learning are needed.

57.

Title	"Letting go": the dissolution of a voluntary organization ... and the lessons learned.
Author(s)	Oake-Vecchiato J, Skelton-Green JM
Journal	Can J Nurs Adm
Pub. Date	1997, Nov-Dec v.10/4
Pages	45-64
Abstract	Birthing and Mother-Baby Centre, Doctors Hospital, Toronto. Like other businesses in North America, the Canadian health care system is undergoing significant and widespread change. It is inevitable in these times that some organizations, some structures, some units will become irrelevant in their existing forms, and should be fundamentally altered, or discontinued altogether. The need for such decisions is too often resisted, denied or avoided. Voluntary organizations and associations are particularly vulnerable to the forces of change and transition. These organizations are as likely as any other to need reexamination, and perhaps even more likely to "miss the signals" heralding a need for redesign. There aren't many examples of voluntary groups which have either discontinued their operations, or radically changed their mandates; the Toronto Association for Quality in Health Care (TAQHC) is one such organization. It is the authors' hope that by sharing TAQHC's decision and process for dissolution we may be able to assist other organizations facing similar challenges. It is further our belief that many of the lessons learned from this experience are applicable to situations other than those of voluntary organizations.

58.

Title	The Strategic Agenda For Community-Health Care Organizations
Author(s)	Griffith JR
Journal	HEALTH CARE MANAGEMENT REVIEW
Pub. Date	1997 SUM v.22/3
Pages	82-91
Abstract	This article proposes a vision, strategies, and structure for the organizations that will replace community hospitals. The vision must embrace health rather than health care, and cast reduction as an explicit, measured goal. Strategies must include immediate cost savings, but also longer-term revision of organizations, wage structures, prevention, and medical attitudes. Structures must assure local stakeholders their voice in health issues

59.

Title	Environmental change and organizational evolution: reconsidering the niche of community-based AIDS organizations
Author(s)	Cain R
Journal	AIDS Care
Pub. Date	1997 Jun v.9/3
Pages	331-44
Abstract	This paper examines the changing role of AIDS service organizations (ASOs) in the provision of community-based HIV services. The paper draws on a study of the development of ASOs that is based on in-depth interviews with about 250 individuals involved in the provision of HIV-related community-based services in 12 cities in Canada. Findings indicate how the broadening and increasingly complex needs confronting ASO workers are leading them to become more focused in their efforts. The paper also shows how ASOs are having to reassess their ties to other service organizations and, often, to redefine their mandate in the light of the changing needs associated with HIV. The paper explores some of the problems associated with these changes, and suggests how changing service needs require a renewed commitment on the part of ASOs to work at the level of advocacy and political change

60.

Title	Evaluation of the Heart and Stroke Foundation of Canada Research Scholarship Program: research productivity and impact
Author(s)	Armstrong PW, Caverson MM, Adams L, Taylor M, Olley PM
Journal	Can J Cardiol
Pub. Date	1997 May v.13/5
Pages	507-16
Abstract	To compare the research productivity, and its impact, of individuals awarded research scholarships from the Heart and Stroke Foundation of Canada (HSFC) with that of a parallel group of unsuccessful applicants during the funding years 1980/81 to 1989/90 inclusive. Research productivity was defined as the number of peer reviewed publications, and impact was evaluated from the number of publications cited; the number of citations per publication; the number of citations per individual; and the impact score. STUDY SELECTION: Data were collected on 192 individuals. Cohorts were defined as successful and unsuccessful individuals entering the system in the same year. The study comprised 10 separate cohorts. Data were collected on yearly publications and citation counts for each individual. These data, along with journal impact factors, were obtained from the Institute for Scientific Information. CONCLUSIONS: During the 10 years of the study, individuals funded by the HSFC published more papers, more of their papers were cited, and they received more citations per individual than the unfunded comparison group. This consistency in multiple indicators provides strong evidence that funded individuals are more productive and that their work has a greater impact on the body of knowledge in this area. Although this study cannot unequivocally show a direct causal relation between funding and research success, the trend as shown by the indicators studied suggests a beneficial effect.

61.

Title	Health-Care Charities Being Squeezed As More Doors Get Slammed In Canvassers Faces
Author(s)	Gray C
Journal	CANADIAN MEDICAL ASSOCIATION JOURNAL
Pub. Date	1996, JUL 15 v.155/2
Pages	229-231
Abstract	Canada's health care charities are beginning to feel the pinch as Canadians tighten their financial belts. They are in a struggle to maintain donation levels because of the tough economy, increasing competition for dwindling dollars and changing social patterns that affect traditional fund-raising efforts. Yet as governments cut health care funding and hospitals eliminate services, charities are being asked to play a greater role in patient education, research funding and service delivery. Their response is to explore new ways to raise money and to continue to lobby for changes in the tax system.

62.

Title	The Feather of Hope Aboriginal AIDS Prevention Society: a community approach to HIV/AIDS prevention
Author(s)	Mill JE, DesJardins DA
Journal	Can J Public Health
Pub. Date	1996 Jul-Aug v.87/4
Pages	268-71
Abstract	Infection with the human immunodeficiency virus (HIV) is a complex and challenging issue for Aboriginal people in Canada. There is a need for HIV/AIDS prevention programs that address the specific needs of Canadian Aboriginal communities in a culturally accepted manner. The Feather of Hope Aboriginal AIDS Prevention Society provides culturally sensitive HIV prevention programs to Aboriginal communities in Alberta. The community development approach used by the Society emphasizes empowerment at the individual and group level. This approach is congruent with the shift to self-determination by Aboriginal people throughout Canada.

63.

Title	A community development and outreach program in geriatric mental health: four years' experience
Author(s)	Stolee,-Paul; Kessler,-Linda; Le-Clair,-J.-Kenneth
Journal	Journal of the American Geriatrics Society
Pub. Date	1996 Mar. v.44
Pages	314-20
Abstract	The writers describe a geriatric mental health outreach program based on a community development model and review four years of experience with this program. Located in Ontario, Canada, the program focuses on community-dwelling or institutionalized older persons who have late-onset mental health problems and/or behavior disturbances, persons with long-standing psychiatric disorders with age-related changes, and their caregivers. Elements of this program include an interprofessional consultation team, a specialized information and resource service, educational service initiatives, and an ongoing role in planning and coordination activity in the local health-care system. Experience with the program indicates that cognitive impairment, behavioral disturbance, physical/medical problems, and depression are the most common reasons for referral. So far, the program has revealed evidence of the feasibility and potential benefits of a comprehensive approach to community development and outreach in geriatric mental health.

64.

Title	The Canadian Heart Health Initiative: Dissemination perspectives
Author(s)	Stachenko, S
Journal	CANADIAN JOURNAL OF PUBLIC HEALTH-REVUE CANADIENNE DE SANTE PUBLIQUE
Pub. Date	1996, NOV-DEC v.87/2
Pages	S57-S59
Abstract	The Canadian Heart Health Initiative is a country-wide strategy for the prevention of cardiovascular disease. Initiated with a 15-year horizon, it has resulted in extensive networks and coalitions involving Health Canada, the 10 provincial departments of health and over 1,000 organizations. There are five phases: policy development through country-wide consultations (1986-88); provincial heart health surveys (1986-91); research demonstration programs (1989-97); and evaluation (1994-97). The dissemination research phase studies the adoption of interventions by communities and health systems. As a paradigm for dissemination of health policy, some key features of the Initiative are: translation of the science base in prevention into community programs; consensual policy development; federal and provincial co-funding arrangements; key role played by the public health system; capacity building; organization and management model linking activities at the national, provincial and community levels. The methodologies and capacities developed are applicable to other health promotion and disease prevention areas.

65.

Title	Knowledge, skills and experiences for community health nursing practice: The perceptions of community nurses, administrators and educators
Author(s)	Bramadat, IJ; Chalmers, K; Andrusyszyn, MA
Journal	JOURNAL OF ADVANCED NURSING
Pub. Date	1996, DEC v.24/6
Pages	1224-1233
Abstract	Nursing in Canada is committed to preparing all new graduates at the baccalaureate level for entry to nursing practice by the year 2000. This goal has major implications for community health nursing education and practice. Health care reform is also expected to move care out of the hospital and into the community. It was against this backdrop that the researchers mounted a study on the educational preparation needed for graduates to begin to practice community health nursing. In this paper, the knowledge, professional and personal skills, and experiences that graduates need to begin community practice are reported. The study was carried out within an action-research framework. All major groups of stakeholders involved in community health nursing throughout the study province were involved in the project. This included nurses and administrators from two public health agencies (provincial and municipal), home care nurses, home health nurses (i.e. non-governmental visiting nurses), community health centres, provincial health care and nursing consultants, and faculty from two universities. In addition to the generation of relevant research findings for use by the educational institutions, the study was initiated to set the stage for future and ongoing interactions between the researchers and community experts to implement the findings from the project. Data were collected from 118 participants by means of 27 focus groups of community nurses, administrators and educators. Interviews were tape-recorded, transcribed and analysed using latent content analysis and constant comparison techniques. Findings indicated that qualified nurses from university programmes need a wide range of knowledge, skills and experiences to begin to practice community health nursing. Detailed accounts of these requirements are outlined and the implications for practice and education put forward.

66.

Title	The development of community care policy for the elderly: A comparative perspective
Author(s)	Litwin, H; Lightman, E
Journal	INTERNATIONAL JOURNAL OF HEALTH SERVICES
Pub. Date	1996, v.26/4
Pages	691-708
Abstract	A comparison of the development of community care for the elderly in the province of Ontario, Canada, and in the State of Israel is presented in the light of the economic constraints currently challenging the expansion of welfare state services. The inquiry identified several common issues regarding the nature of the policy mandate for long-term care delivered in the home, the structure of the service delivery system, and matters concerning funding arrangements for community care. Issues that emerged in both settings include the relationship between health and social services in the delivery of care at the local level; the separation of purchaser and provider functions; the question of needs-driven versus service-driven social care provisions; accessibility concerns and the aspiration for one-stop entry to the delivery system; the growing involvement of the private sector in the delivery of domiciliary-based personal care services; and the relative paucity of current efforts to address the needs of family caregivers.

67.

Title	Community control of health services for Canadian Indians
Author(s)	Walters, JF; Ankomah, A
Journal	WORLD HEALTH FORUM
Pub. Date	1996 v.17/3
Pages	242-245
Abstract	Many countries have a dominant culture and one or more minorities. Can a single type of health care therefore meet the needs of diverse populations? The health situation among the Indian populations in Canada could be improved by the ''health transfer'' initiative, which is described below

68.

Title	Health care advocacy turns into political activism
Author(s)	Spears T
Journal	CMAJ
Pub. Date	1995 May 15 v.152/10
Pages	1679-81
Abstract	Some advocacy groups are becoming more willing to engage in political activism. One is the Ontario Lung Association, which has been calling attention to government inaction on air-pollution issues such as controlling smog and improving indoor air quality. These lobbying efforts are supported by some physicians, who believe that environmental factors are behind the increased incidence of respiratory illness

69.

Title	Public Funds, Private Provision, The Role Of The Voluntary Sector
Author(s)	Mellon H
Journal	JOURNAL OF CANADIAN STUDIES-REVUE D ETUDES CANADIENNES
Pub. Date	1995 FAL v.30/3
Pages	223-231
Abstract	N/A

70.

Title	Coeur En Sante St-Henri - A Heart Health Promotion Program In Montreal, Canada - Design And Methods For Evaluation
Author(s)	Oloughlin, J et al.
Journal	JOURNAL OF EPIDEMIOLOGY AND COMMUNITY HEALTH
Pub. Date	1995, OCT v.49/5
Pages	495-502
Abstract	Study objective - This paper describes the objectives, design, and methods of evaluation of the impact of the coeur en sante St-Henri programme, as well as selected results from the evaluation to date. It discusses the possible effects of study design choices made to maintain the impact evaluation within budget. Design - The impact of the programme is evaluated in a community trial which compares the prevalence of cardiovascular disease behavioural risk factors before and after programme implementation in the intervention and a matched comparison community, in both longitudinal cohort and independent sample surveys. In addition, repeated independent sample surveys are conducted in the intervention community to monitor awareness of and participation in the programme. Participants - The baseline sample for both the longitudinal cohort and independent sample surveys included 849 subjects from the intervention community (79.3% of 1071 eligible subjects - 8.0% could not be contacted and 12.6% refused) and 825 subjects from the comparison community (77.8% of 1066 eligible subjects - 6.6% could not be contacted and 15.6% refused). The two surveys on awareness and participation conducted to date, included 461 (71.0% of 649 eligible subjects) and 387 (67.9% of 570 eligible subjects) subjects respectively from the intervention community. Measurements - Baseline data for the longitudinal cohort and independent sample surveys on behavioural risk factor outcomes including use of tobacco, physical activity behaviour, high fat diet, and behaviours related to blood pressure and cholesterol control were collected in 35 minute telephone interviews in bath the intervention and comparison communities. Data on awareness of and participation in the programme were collected in 10 minute interviews in the intervention community only in two independent sample surveys conducted seven and 22 months respectively after the baseline survey. Results - With the exception of smoking, the intervention and comparison communities were similar at baseline with regard to the prevalence of behavioural risk programme increased from 64.1% in January 1993 to 72.9% 15 months later. Participation in the programme increased from 21.3% to 33.7%. Conclusions - This paper presents background information on the evaluation of the impact of the coeur en sante programme, as a reference for future publications.

71.

Title	Coeur En Sante St-Henri - A Heart Health Promotion Program In A Low-Income, Low Education Neighborhood In Montreal, Canada - Theoretical-Model And Early Field Experience
Author(s)	Paradis, G et al.
Journal	JOURNAL OF EPIDEMIOLOGY AND COMMUNITY HEALTH
Pub. Date	1995, OCT v.49/5
Pages	503-512
Abstract	Study objective - Coeur en sante St-Henri is a five year, community based, multifactorial, heart health promotion programme in a low income, low education neighbourhood in Montreal, Canada. The objectives of this programme are to improve heart-healthy behaviours among adults of St-Henri. This paper describes the theoretical model underlying programme development as well as out early field experience implementing interventions. Design - The design of the intervention programme is based on a behaviour change model adapted from social learning theory, the reasoned action model, and the precede-proceed model. The Ottawa charter for health promotion provided the framework for the development of specific interventions. Each intervention is submitted to formative, implementation, and impact evaluations using simple and inexpensive methods. Participant - The target population consists of adults living in St-Henri, a neighbourhood of 23 360 residents. Because of costs constraints, the intervention strategy targets women more specifically. The community is one of the poorest in Canada with 46% of the population living below the poverty line and 20% being very poor. The age-sex adjusted ischaemic heart disease mortality in 1985-87 was 317 per 100 000 compared with 126 per 100 000 in an affluent adjacent neighbourhood. Results - Thirty nine distinct interventions have been developed and tested in the community, eight related to tobacco, 10 to diet, seven to physical activity, and 14 which are multifactorial. The interventions include smoking cessation and healthy recipes contests, a menu labelling and healthy food discount programme in restaurants, a point of choice nutrition education campaign, healthy eating and smoking cessation workshops, a walking club, educational material, print and electronic media campaigns, heart health fairs, and community events. Conclusion - An integrated heart health promotion programme is feasible in low income urban neighbourhoods but not all intervention are successful. Such a programme requires substantial energy and resources as well as long term commitment from public health departments.

72.

Title	Use Of Medical-Care After A Community-Based Health Promotion Program - A Quasi-Experimental Study
Author(s)	Cousins, M; McDowell, I
Journal	AMERICAN JOURNAL OF HEALTH PROMOTION
Pub. Date	1995, SEP-OCT v.10/1
Pages	47-53
Abstract	Purpose. To assess the effects of health promotion on the use of medical care services in a community setting. Design. Quasi-experimental, multiple time points, case-comparison group. Setting Community health center in Ottawa, Canada. Sample. 520 volunteer participants in a health promotion program and 932 matched comparison subjects. Intervention. The health promotion program consisted of a weekend workshop on health behaviors, lifestyle assessment, and identification of weekly goals for change. This was followed by 18 months of support (5 group sessions, weekly telephone calls, and optional individual sessions). Measurement, Computerized data on health care use 6 months before, 18 months during, and 6 months after the program were obtained from Ontario's universal Health Insurance Plan (OHIP). These data were used to determine the number and system costs of visits made by participants and comparisons. Results. When controlling for baseline differences through analysis of covariance, program participants were found to have higher costs and more visits for ambulatory care during the first year ($p < .01$) and second year ($p < .05$) of follow-up. Participants used significantly more diagnostic services than comparisons during both years of follow-up. Participants were also more likely to use more counseling and psychotherapy services in year 1 (relative with 1.53; 95% confidence interval, 1.28, 1.81) and year 2 (relative risk 1.57; 95% confidence interval, 1.31, 1.89. No differences were found between participant and comparison groups in visits for medical consultations and assessments or preventive services. Conclusion. No evidence shows that this health promotion program reduced use in this population over the 2-year follow-up period.

73.

Title	Service Models In Community-Based Health - Some Findings From A Literature-Review
Author(s)	Crichton, AO; Robertson, A; Farrant, W
Journal	CANADIAN JOURNAL OF PUBLIC HEALTH-REVUE CANADIENNE DE SANTE PUBLIQUE
Pub. Date	1995, JAN-FEB v.86/1
Pages	26-28
Abstract	The findings from a review of the literature on community-based health services in Canada in 1991 indicate that two systems of health care exist side by side: the clinical care of the sick and the supportive care of those seeking to keep well. Organizational models of clinical care have not altered much since the introduction of health insurance. The medical profession has been resistant to changing traditional forms of practice organization from fee-for-service businesses treating individuals in isolation to components of an integrated comprehensive health care system. Traditional public health departments offering supportive and preventive care have been more ready to adapt to change. They are now working closely with provincial continuing-care organizers to provide home care for those who might otherwise need institutional care; however they are not closely linked with the clinical care services. More recently, public health departments have engaged in the health promotion movement to give citizens increased control over the conditions affecting their health. Yet we perceived a conflict between the rhetoric and the reality of their work.

74.

Title	Community-based AIDS organizations and the state: dilemmas of dependence
Author(s)	Cain,-Roy
Journal	AIDS and Public Policy Journal.
Pub. Date	1995, Summer v.10
Pages	83-93
Abstract	The writer examines how the success of the AIDS movement in acquiring state funding and support for AIDS service organizations (ASOs) can paradoxically work to undermine the ability of community-based AIDS organizations to meet the longer-term objectives of the movement. ASO workers require state funding and want to nurture supportive links with government workers, but they worry about inadequate levels of funding, government attempts to control their work, censorship of their prevention campaigns, and onerous reporting requirements. In addition, they are concerned about a range of less readily visible tensions.

75.

Title	The recent evolution of assessment/referral centers and current directions
Author(s)	Pierce,-Stephen
Journal	Contemporary-Drug-Problems
Pub. Date	1995 Spring v.22
Pages	105-14
Abstract	Part of a special section on the development of assessment/referral addictions treatment programs in Ontario, Canada. During the late 1970s and early 1980s, assessment/referral (A/R) centers were identified as an element of a comprehensive continuum of addiction services for the province of Ontario, and at the same time, the Ontario Provincial Ministry of Health began to shift its emphasis from institutional/residential treatment to community-based, or outpatient, services. It was presumed that A/R centers would facilitate this process by helping clients to identify the least intrusive form of treatment required, and in this way, the development and evolution of A/R services was an integral aspect of the provincial addiction system's development. The processes and procedures involved in the operation of a typical A/R center are discussed in terms of admission criteria, referral sources, intake and orientation, assessment, and treatment planning. The current climate of restraint and cutbacks and the uncertain future of A/R centers are considered.

76.

Title	The NCIC/CCS behavioral initiative. National Cancer Institute of Canada Canadian Cancer Society
Author(s)	Iverson DC
Journal	Can J Oncol
Pub. Date	1994 Apr v.4/2
Pages	255-61
Abstract	The NCIC's behavioral initiative is comprised of three pillars, each of which is designed to make an important independent contribution toward a reduction in cancer incidence, morbidity or mortality rates. It is also expected that the activities in one area will complement those in the other areas, thereby creating a synergistic effect. To determine if the objectives of the Centre for Behavioral Research and Program Evaluation (CBRPE) are being met, the NCIC has committed to an ongoing assessment of the CBRPE's performance, including an independent review of its scientific merit by a site visit conducted at the end of the second year of the CBRPE's operation. Thus, while the behavioral initiative represents a different type of investment by the NCIC, its contributions will be judged via a process that is central to all NCIC activities--the assessment of scientific merit by teams of persons recognized nationally and internationally for their expertise in social and behavioral research as it pertains to cancer.

77.

Title	Community-based facilities may be replacing hospitals for the treatment of alcoholism: the evidence from Ontario
Author(s)	Adrian,-Manuella, 1947-; Ogborne,-Alan-C; Rankin,-James-G
Journal	American Journal of Drug and Alcohol Abuse
Pub. Date	1994 v.20/4
Pages	529-45
Abstract	The utilization of hospitals and of community facilities for the treatment of alcohol problems in Ontario was investigated. Data from Statistics Canada, Hospital Medical Records Institute records, and other administrative sources show that between 1974 and 1986 there was a large reduction in utilization of hospital services for treatment of alcohol problems. These data also show that there was a simultaneous increase in overall availability of hospital beds and bed-days of care for all medical conditions, with no change in total number of hospital discharges or occupancy rates. Over the period, there was also an increase in the number of community-based programs for the treatment of alcohol problems and in the number of persons or cases treated by these programs. This increase was associated with a reduction of inpatient cases treated for alcohol problems in 38 of 48 counties in Ontario.

78.

Title	Agency and Efficiency in Nonprofit Organizations: The Case of "Specific Health Focus" Charities
Author(s)	Callen, Jeffrey L; Falk, Haim
Journal	Accounting Review,
Pub. Date	1993 January v.68/1
Pages	48-65
Abstract	N/A

79.

Title	Emergency shelters in Vancouver, Canada
Author(s)	Acorn,-Sonia
Journal	Journal of Community Health
Pub. Date	1993 Oct. v.18
Pages	283-91
Abstract	The shelter experiences, employment history, income and social service needs utilization were examined among 124 emergency shelter users in Vancouver, British Columbia. Thirty-six (30.5%) reported this as their first experience with living in a shelter; the length of stay in the present shelter ranged from one to 90 days. Reasons for shelter use included: eviction from last place of residence, loss of job, or suffering from health problems rendering one unable to work. The highest unmet service needs were finding affordable housing and finding a job. This combination of scarcity of low-cost housing, health problems, and difficulty in finding employment have led to a situation where emergency shelters have become extended places of residence, a "home" to many.

80.

Title	The Multi-Service Network: reaching the unserved multi-problem individual
Author(s)	Buckley,-Ralph; Bigelow,-Douglas-A
Journal	Community Mental Health Journal
Pub. Date	1992 Feb. v.28
Pages	43-50
Abstract	N/A

81.

Title	Impact of the Private Non-profit Sector on the Distribution of Canadian Health Research Funding
Author(s)	O'Brecht, Michael; Doutriaux, Jerome
Journal	Canadian Public Policy
Pub. Date	1992 September v.18/3
Pages	290-99
Abstract	The distribution of funding for health research by region and subject area can indirectly influence the quality and breadth of health care. This empirical analysis examines the impact of funding from private non-profit agencies, governments, industry, and universities on the distribution of health research resources. The contribution of private non-profit agencies is examined in detail to illustrate its effect on the distribution of health research funding by region and disease area. Findings offer insight into the interaction of private and public sector research funding, the role of the private non-profit agencies in Canadian health research, and the importance of public sector grants in maintaining a research capacity across regions and in disease areas that have a low public profile.

82.

Title	Competition increasing in the fundraising arena
Author(s)	N/A
Journal	Northern Ontario Business
Pub. Date	1992 September v.12/12
Pages	1,11
Abstract	Fundraising has become competitive and energy-intensive for non-profit organizations, with the number of charities in Canada jumping to 61,000 in 1992 from 39,000 in 1982. Northern Ontario Director Joanna Miller of Canadian National Institute for the Blind (CNIB) said pledges were down so they had to work harder. CNIB branches in Northern Ontario joined with cancer, kidney, and diabetes associations to share the volunteer workload. Canadian Mental Health Assn plans three major fundraising events instead of many small ones, with the aim of making as many people as possible aware of it. Kidney Foundation of Canada's Northeastern Ontario chapter also rationalized its fundraising event s and raised $16,000 in 1992 compared with $6,000 in 1991. Red Cross said the challenge is to come up with different ideas. A rock and roll revival in Sudbury and a Christmas poinsettia sale in Timmins each netted more than $10,000. Most United Way/Centraide donations come from employee payroll deductions so its drive is to increase the donor base

83.

Title	Charities often overlooked as vital part of the economy
Author(s)	N/A
Journal	Northern Ontario Business
Pub. Date	1992 September v.12/12
Pages	10
Abstract	Social service organizations such as the Salvation Army boost the Northern Ontario economy through their work. Some branches of Canadian National Institute for the Blind (CNIB) belong to local Chambers of Commerce and consider themselves part of the business community while remaining non-profit. Canadian Red Cross Society and Canadian Mental Health Assn are other agencies to claim a contribution to the economy through their delivery of low-cost social services, mobilizing large numbers of volunteers. CNIB's seven northern branches with about 100 paid staff have a combined annual budget of $3.4m. The Sudbury office of Mental Health Assn alone has an annual budget of $1m and Red Cross, with 13 northern branches, a budget of about $800,000

84.

Title	Advantages in amalgamation for two small non-profit health care agencies
Author(s)	Martin-C
Journal	The-Social-Worker-Le-Travailleur-social
Pub. Date	1992, Winter v.60/4
Pages	213-15
Abstract	An agency whose mandate is to provide information and social support to a patient population suffering from a relatively uncommon disorder is unlikely to have the resources to provide high quality service. The client group may not be a large enough pool from which to draw the natural leaders needed for self-help and for public awareness. The statistical profile, with its low numbers does not easily attract either corporate or philanthropic funding. Consequently, the agency is at a disadvantage in recruiting and retaining high-caliber staff and attracting citizens to serve as board members. The answer may lie in sharing resources with another agency. This article describes the process by which the Victoria Epilepsy Association and the Victoria Parkinson's Disease Association amalgamated. Both the positive and negative aspects of such an amalgamation are discussed

85.

Title	AIDS, hospice and volunteers. The Casey House volunteer program. A case study
Author(s)	Murrant G, Strathdee S
Journal	J Volunt Adm
Pub. Date	1992, Summer v.10/4
Pages	11-7
Abstract	N/A

86.

Title	The health network: an alternative form of care delivery
Author(s)	Holt AA
Journal	Leadersh Health Serv
Pub. Date	1992 Nov-Dec v.1/6
Pages	25-6
Abstract	The Health Network, a community and social service organization of volunteers and a small staff aims to serve three suburban and rural communities west of Ottawa. In June 1991, the Health Network approached Ontario's Ministry of Health for funding of community-based health services for these municipalities. In light of decreasing resources in hospitals, this article reviews how the Health Network became organized and summarizes a community needs assessment complete in September 1989.

87.

Title	Non-profit providers of mental health care: privileges and responsibilities
Author(s)	Frank-R-G; Salkever-D-S
Journal	Administration-and-Policy-in-Mental-Health.
Pub. Date	1991, Jan. v.18/3
Pages	195-98
Abstract	Although valid questions have been raised about the performance of individual nonprofit providers in supplying nonremunerative services to the community, it is clear that on average nonprofit mental health providers have played a key role in filling in as publicly provided services have been cut back and/or privatized. This article explains the privileges and responsibilities of the nonprofit sector, reports on the costs of community services by nonprofits, and suggests future policy directions.

88.

Title	Community Health Centers: Do they Pose a Threat to fee-for-service Medicine
Author(s)	Morgan, PP; Cohen L
Journal	CMAJ
Pub. Date	1991, v.144/6
Pages	
Abstract	N/A

89.

Title	A diocese as owner
Author(s)	De Roo R
Journal	CHAC Rev
Pub. Date	1990 Summer v.18/2
Pages	17-20
Abstract	For 76 years, the Sisters of St. Joseph of Toronto provided dedicated and skillful service in the Comox Valley. The Sisters witnessed to the three essential elements of nursing: compassionate care, efficient promotion of health and faithful commitment to the health care profession. The Sisters have left a wonderful heritage which the diocese is committed to maintain

90.

Title	Brief program report: providing medical care to mentally ill women in the community: multi-service program in Toronto, Ont.
Author(s)	Heyding,-Robert-K
Journal	Community Mental Health Journal
Pub. Date	1990 Aug. v.26
Pages	373-8
Abstract	N/A

91.

Title	When Will Community Health Centers Join the Mainstream?
Author(s)	Daly, D
Journal	Health Care
Pub. Date	1989, Jul/Aug.
Pages	
Abstract	N/A

92.

Title	"We'll take care of it for you" health care in the Canadian community
Author(s)	Evans,-Robert-G
Journal	Daedalus
Pub. Date	1988 Fall v.117
Pages	155-89
Abstract	N/A

93.

Title	The Impact of Public health Policy: The Case of Community Health Centers.
Author(s)	Goldman, F; Grossman, M
Journal	Eastern Economic Journal.
Pub. Date	1988, v.14/1
Pages	62-73
Abstract	N/A

94.

Title	The health promotion role of the community development worker.
Author(s)	Rovers,-Ria
Journal	Canadian-Journal-of-Development-Studies/Revue-Canadienne-d'Etudes-du;
Pub. Date	1986 Summer n.7
Pages	301-10
Abstract	Focuses on the program of the Coady International Institute, St. Francis Xavier University, Nova Scotia; a training center for students from Third World countries to assist them in improving conditions in their homelands

95.

Title	Does community care for the mentally ill make a difference? a tale of two cities
Author(s)	Beiser,-Morton; Shore,-James-H; Peters,-Ron
Journal	The American Journal of Psychiatry
Pub. Date	1985 Sept v.142
Pages	1047-52
Abstract	N/A

96.

Title	Forum identifies differences between for-profit and not-for-profit boards
Author(s)	N/A
Journal	Trustee;
Pub. Date	1985 Jun v.38/6
Pages	18-20
Abstract	In late 1984, the first Chaiker Abbis Invitational Forum on Hospital Governance was held in Montreal, Canada. The forum brought together a group of prominent health care leaders from the United States and Canada to discuss some of the similarities and differences between for-profit corporate boards and not-for-profit hospital boards. The following report examines the participants' views on the major differences between the two groups

97.

Title	Imaginary Health (Le Sante imaginaire)
Author(s)	Dumais, Alfred
Journal	Recherches Sociographiques
Pub. Date	1982, Sept-Dec v.23/3
Pages	275-284
Abstract	Underlying social causes of the emergence of "self-health" groups in Quebec, Canada, are examined. These voluntary organizations separate themselves from the medical establishment & seek to decentralize health care among community clinics. The institutional crisis in technological societies is discussed, along with the monopolistic nature & the inadequacies of the medical profession. The importance of the concept of autonomy is seen as part of a new mythology of social action. Empirical study of the "self-health" groups would reveal the dialectical relationship between scientific & popular culture

98.

Title	Community Health Centers: An Initiative of Enduring Utility
Author(s)	Freeman, HE; Kiecolt, KJ; Allen II HM
Journal	Millbank Memorial Quarterly
Pub. Date	1982, v.60/2
Pages	245-67
Abstract	N/A

99.

Title	Canadian Catholic health care leaders face the issues: government relations, sponsorship, Catholic identity, medical-moral problems, health insurance programs
Author(s)	MacNeil E, Quaglia LA, Myatt M
Journal	Hosp Prog
Pub. Date	1980 Oct; v.61/10
Pages	35-42
Abstract	N/A

100.

Title	Voluntary health agencies--who, what and why? A survey of the Thames Valley District Health Council Area
Author(s)	Boucher MP, Pablo RY, Roberts JD
Journal	Can J Public Health
Pub. Date	1979 May-Jun v.70/3
Pages	183-98
Abstract	N/A

101.

Title	Community Health centers in Quebec Can Fulfill the need but Compromise is essential
Author(s)	Dion, L
Journal	CMAJ
Pub. Date	1974, v.111
Pages	
Abstract	N/A

Appendix 2 – Books, Manuscripts, Edited Collections

1.

Title	Shifting the paradigm in community mental health towards empowerment and community. Toronto
Author(s)	Nelson, Geoffrey B.
Publisher	University of Toronto Press
Pub. Date	2000
Abstract	N/A

2.

Title	The nonprofit sector in Canada; roles and relationships
Author(s)	Banting, Keith G
Publisher	Montreal, McGill-Queen's University Press
Pub. Date	2000
Abstract	N/A

3.

Title	Community Health Centre Expansion In Ontario: A Business Case for Strengthening Community-Based Primary health Case Services
Author(s)	
Publisher	Association of Ontario Health Centres
Pub. Date	2000
Abstract	N/A

4.

Title	Volunteer Services in CHCs and AHACs: Issues of Management, Support and the Volunteers' Experience in the CHC/AHAC Model of Care
Author(s)	Arai, S
Publisher	Association of Ontario Health Centres
Pub. Date	2000
Abstract	N/A

5.

Title	Building the Relationship Between National Voluntary Organizations Working in Health and Health Canada: A Proposed Framework for Action
Author(s)	Health Canada
Publisher	Health Canada
Pub. Date	1999
Abstract	N/A

6.

Title	Developing a Typology of the Voluntary Health Sector in Canada: Definition and Classification Issues
Author(s)	Febbraro, A; Hall, M; Parmegiani, A
Publisher	Voluntary Health Sector Project, HC
Pub. Date	1999
Abstract	N/A

7.

Title	The Voluntary Health Sector in Canada: Outcomes and Measurement
Author(s)	Barbara Legowski and Terry Albert
Publisher	Voluntary Health Sector Project
Pub. Date	1999
Abstract	N/A

8.

Title	Health Integration in Practice: The Community Health Centres of Ottawa-Carleton
Author(s)	Tanner F
Publisher	Association of Ontario Health centers
Pub. Date	1999
Abstract	N/A

9.

Title	Taking care of each other: field guide, community HIV health promotion: theory, method and practice. Vancouver,B.C.
Author(s)	Trussler, Terry
Publisher	AIDS Vancouver.
Pub. Date	1997
Abstract	N/A

10.

Title	Homeless: Policies, Strategies, And Lives On The Street
Author(s)	Daly, Gerald
Publisher	London, England: Routledge
Pub. Date	1996
Abstract	Describes the institutional & policy contexts that produce homelessness in a comparative examination of GB, Canada, & the US by analyzing the roles & relationships of public & private groups involved in this issue. Drawing on a literature review, analysis of public policy debates, assessment of voluntary sector efforts, & interviews with key actors, a definition of homelessness as those who are absolutely, periodically, or temporally without shelter is offered & a statistical composition of the homeless in the three countries is presented. While the composition of the homeless is similar, differences in government transfer payments during the 1980s when the number of poor households grew in all three countries produced different social policies. Canada was best at reducing the gap between rich & poor through transfer payments & income taxes, while GB reduced its transfer payments to 66% of those of the US. The evolution of responses to homelessness in Western Europe & the US from the 19th century to the present is chronicled, & the meaning of homelessness is ascertained in an analysis of the relationship between health issues, both mental & physical, & homelessness & a description of the experience of homelessness from the perspective of the people involved. Shelter alternatives for the homeless, including community-based housing, are discussed in the context of the response to homelessness by governments at all levels & the voluntary sector. It is suggested that the differing responses of the three countries are due to disparate notions of individual, community, society, & state, concepts shaped by their differing cultures & histories. Recommendations for precluding homelessness are offered.

11.

Title	National Advisory Council on Aging (Canada). NACA position on community services in health care for seniors: progress and challenges.
Author(s)	
Publisher	Ottawa, Supply and Services Canada
Pub. Date	1995
Abstract	Position du CCNTA sur les services se sante communautaires destines aux aine-e-s: progres et defis. Position paper (Canada. National Advisory Council on Aging). N. 16

12.

Title	Mobilizing community resources; highlights of conference '94. Ottawa, Ont
Author(s)	Native Mental Health Association of Canada.
Publisher	Native Mental Health Association of Canada.
Pub. Date	1994
Abstract	Based on information presented during the Native Mental Health Association of Canada's conference held in Ottawa, 1994

13.

Title	Community health Centres: A Picture of Health
Author(s)	Ontario Ministry of Health
Publisher	Ontario Ministry of Health
Pub. Date	1993
Abstract	N/A

14.

Title	Community health Centres
Author(s)	British Columbia Ministry of Health
Publisher	Victoria: British Columbia M of H
Pub. Date	1993
Abstract	N/A

15.

Title	Community health centers and Community development
Author(s)	Hoffman K; Dupont JM
Publisher	Health and Welfare Canada
Pub. Date	1992
Abstract	N/A

16.

Title	An Exploratory study of private home care services in Canada
Author(s)	Nahmiash, Daphne and Reis, Myrna
Publisher	Ottawa: Health & Welfare Canada, Health Services & Promotion Branch, Community Health Division
Pub. Date	1992
Abstract	Summarizes findings of an exploratory study of private home care services for seniors in Canada, involving four main components: interviews; a literature review; four case studies of innovative private home care agencies; and a pilot survey of some private agencies across Canada. The interviews were with 17 key informants in both the public and private home care sectors in Canada and the United States. They were asked to identify major concerns in the private sector and to comment on issues such as public/private collaboration, free trade, training programs, and quality control. The literature review yielded limited material on evaluative and outcome studies, descriptions of the private sector, comparisons of for-profit and non-profit agencies, and innovative home care programs. The case studies included on-site visits and interviews, and characteristics commonly identified as important in the provision of high quality services are noted. The pilot survey elicited basic descriptive information such as staffing, clients, types of services, budgets, fees, quality controls, training, hiring practices, and problems. Three broad areas of concern emerged from the overall findings and conclusions are made regarding the need for improved quality controls and standards, improvements for services, and research and outcome evaluation.

17.

Title	The Involvement of Canadian Native Communities in their health care programs; a review of the literature since the 1970's
Author(s)	Young, David E.
Publisher	Edmonton, Canadian Circumpolar Institute, U. of Alberta.
Pub. Date	1992
Abstract	N/A

18.

Title	Community, environment and health; geographic perspectives
Author(s)	Hayes, Michael V.; Foster, Leslie T.; Foster, Harold D.
Publisher	Victoria, B. C., Dept. of Geography, University of Victoria.
Pub. Date	1992
Abstract	N/A

19.

Title	Helping seniors mobilize; a handbook on community organizing.
Author(s)	Mairs, Beth
Publisher	Toronto, Lawrence Heights Community Health Centre
Pub. Date	1991
Abstract	N/A

20.

Title	Quebec (Province). Commission d'enquete sur les services de sante et les services sociaux. Centres communautaires locaux de services sociaux et de sante: etude comparative Quebec-Ontario. Quebec,
Author(s)	Quiviger, Claude
Publisher	Les Publications du Quebec.
Pub. Date	1987
Abstract	N/A

21.

Title	Quebec (Province). Commission d'enquete sur les services de sante et les services sociaux. Community-initiated health and social services. Quebec.
Author(s)	Shragge, Eric; Letourneau, Taylor
Publisher	Commission d'enquete sur les services de sante et les services sociaux).
Pub. Date	1987
Abstract	N/A

22.

Title	Improving the delivery of community-based health and social services; proceedings of the Ottawa conference, 24-27 November 1985.
Author(s)	Randle, Kathryn
Publisher	Ottawa, Canadian Council on Social Development.
Pub. Date	1986
Abstract	N/A

23.

Title	First and foremost in community health centres; the centre in Sault Ste Marie and the CHC alternative
Author(s)	Lomas, Jonathan
Publisher	Toronto, U. P.
Pub. Date	1984
Abstract	N/A

24.

Title	Community health centre in Canada: vol.1: report of the community health centre project to the Conference of health ministers. 1 v.
Author(s)	
Publisher	Canada. Dept. of National Health and Welfare
Pub. Date	1972
Abstract	N/A

25.

Title	Community health centre in Canada: vol.2: economic characteristics of community health centres. 1972
Author(s)	Ruderman, A. P.
Publisher	Canada. Dept. of National Health and Welfare
Pub. Date	1972
Abstract	N/A

26.

Title	Community health centre in Canada: vol.3: health care organization of the future?
Author(s)	Crichton, Anne
Publisher	Canada. Dept. of National Health and Welfare
Pub. Date	1972
Abstract	N/A

Appendix 3 – Conference Papers

1.

Title	Canadian Health Coalition and the future of Canada's Medical Care System
Author(s)	Connors, K
Sponsor	American Public Health Association
Conference/ Date	124th Annual Meeting and Exposition of the American Public Health Association, New York, NY (USA), 17-21 Nov 1996. (World Meeting Number 964 0837)
Availability	TASCO, 9 Jay Gould Court, Waldorf, MD 20602. Phone: 301-893-1894, Price $30.
Abstract	N/A

2.

Title	Community-based survey for health promotion planning in a minority community: The Korean-Canadians in British Columbia, Canada
Author(s)	Lee, Myoung-Soon; Green, LW; Shannon, WJ; Ratner, PA
Sponsor	American Public Health Association
Conference/ Date	124th Annual Meeting and Exposition of the American Public Health Association, New York, NY (USA), 17-21 Nov 1996. (World Meeting Number 964 0837)
Availability	TASCO, 9 Jay Gould Court, Waldorf, MD 20602. Phone: 301-893-1894, Price $30.
Abstract	Poster Paper

3.

Title	The royal society of Canada study of participatory research in health promotion
Author(s)	Green, LW
Sponsor	Japan Organizing Committee; Japan Wellness Foundation in the name of IUHPE; International Union for Health Promotion and Education
Conference/ Date	XV World Conference of the International Union for Health Promotion and Education, Makuhari (Japan), 20-25 Aug 1995. (World Meeting Number 953 0910)
Availability	Secretariat for the 15th World Congress of IUHPE, c/o Dept. of Public Health, School of Medicine, Juntendo University, 2-1-1 Hongo, Bunko-ku, Tokyo, Japan. Phone:81-3-5802-1049; Fax: 81-3-3814-0305
Abstract	N/A

4.

Title	Influencing agencies and voluntary organizations
Author(s)	Myers, M
Sponsor	Canadian Council on Smoking and Health
Conference/ Date	Smoking and Health, Fifth World Congress, Winnipeg, Manitoba, Canada, 10-15 Jul 83. (World Meeting Number 833 0083)
Availability	Proceedings available in 1984. For information: Dr. D. Nostbakken, Dir. Public Educ., Canadian Cancer Soc., 130 Bloor St. W, Suite 1001, Toronto, Ont. M5S 2V7
Abstract	N/A

5.

Title	Anti-smoking health education carried out by voluntary organizations after the enforcement of the Finnish Tobacco Act
Author(s)	Elovainio, L; Klemola, J; Koshinen-Ollongvist, P; Paavilainen, S
Sponsor	Canadian Council on Smoking and Health
Conference/ Date	Smoking and Health, Fifth World Congress, Winnipeg, Manitoba, Canada, 10-15 Jul 83. (World Meeting Number 833 0083)
Availability	Proceedings available in 1984. For information: Dr. D. Nostbakken, Dir. Public Educ., Canadian Cancer Soc., 130 Bloor St. W, Suite 1001, Toronto, Ont. M5S 2V7,
Abstract	N/A

6.

Title	Voluntary health organization as "honest broker" of a smoking cessation program
Author(s)	Hackbarth, D; Gruder, CL; Brickman, S
Sponsor	Canadian Council on Smoking and Health
Conference/ Date	Smoking and Health, Fifth World Congress, Winnipeg, Manitoba, Canada, 10-15 Jul 83. (World Meeting Number 833 0083)
Availability	Proceedings available in 1984. For information: Dr. D. Nostbakken, Dir. Public Educ., Canadian Cancer Soc., 130 Bloor St. W, Suite 1001, Toronto, Ont. M5S 2V7,
Abstract	N/A

Appendix 4. – Unpublished Dissertations/Theses

1.

Title	Perceived stigma and community integration among people with serious mental illness served by assertive community treatment teams.
Author(s)	Prince, Pamela N.
University	(Ph.D.) - Carleton University, Ottawa.
Date	1999
Abstract	N/A

2.

Title	Private interests or the public interest? a critical examination of the role of stakeholder groups in the development of phase one of a long term care policy in Ontario--1989 to 1994 (Canada)
Author(s)	Spindel, Patricia A
University	University of Toronto,
Date	1996
Abstract	This thesis analyzes the role that stakeholder groups representing seniors, people with disabilities, service providers--both for-profit and not-for-profit, unions, and the Ontario Ministry of Health bureaucracy, played in attempting to influence the development of Phase One of long term care policy and legislation in Ontario, leading up to the passage of Bill 101 The Long Term Care Statute Law Amendment Act (1993).There has been very little written about the long term care reform process which took place in Ontario from 1989 to 1994. This thesis attempts to fill this gap in the academic literature. Most of the information for this work comes from interviews with stakeholder representatives, stakeholder exhibits to the Standing Committee on Social Development, documents furnished by stakeholder groups, archival sources, such as Hansard, policy and position papers from government Ministries, internal briefing documents from the Ministry of Health, and financial information from the Ministry of Finance. This material shows how the commercial nursing home industry benefited from the reform of the long term care system, while non-profit homes for the aged, residents, and unions lost ground. Based upon a neo-Marxist, state theory perspective, it is argued that the outcome of the long term care reform initiative was the result of unequal power relations between diverse stakeholder groups which included the Ministry of Health bureaucracy. It is also argued that the state as a whole was in a somewhat ambivalent position vis-à-vis the demands of stakeholder groups towards the end of the reform process. Some members of the Ministry of Health bureaucracy appear to have made significant attempts to address the needs of the commercial nursing home sector, while elected officials, in particular the Minister of Health sought to maintain social harmony, by promising reforms beneficial to consumers of long term care. Together, public officials and civil servants secured the continued legitimacy of the existing socio-economic order in long term care. This study shows that the Ministry of Health succeeded in meeting the needs of business, while imposing its internal cost containment and system rationalization agenda on other stakeholders. This was done primarily at the expense of residents, and the non-profit institutional system, and, to a somewhat lesser extent, at the expense of labour. In spite of promises by the Minister of Health that the long term care reform would result in a more streamlined, accessible, and accountable system for service users, this study will show that it was service users who bore increased costs, and received the same or less care and accountability. This occurred because no stakeholder group was able to effectively challenge the socio-economic structure of the institutional long term care system, which is dominated by the commercial nursing home sector, and supported by the Ministry of Health bureaucracy.

3.

Title	Can community participation be measured in community health centres.
Author(s)	Artelle, Jean
University	(M.S.W.) - Carleton University,
Date	1994
Abstract	N/A

4.

Title	Health Politics and Structural Interests: the development of community health centres in Ontario
Author(s)	Church, W.J.B.
University	University of Western Ontario, London, Ph.D.
Date	1994
Abstract	N/A

5.

Title	The Community Health Centre: Health Planning for Critical Consciousness?
Author(s)	Suschnigg, C.
University	York University, Toronto, Ph.D.
Date	1992
Abstract	N/A

6.

Title	An Analysis of the Graham report: "Building community support for people: a plan for community mental health in Ontario".
Author(s)	Gionet, Roger
University	(M.S.W.) - Carleton University,
Date	1994
Abstract	N/A

7.

Title	From women's benevolence to professional social work: the case of the wimodausis club and the earlscourt children's home, 1902-1971 (volunteer work, child welfare services)
Author(s)	Baines, Carol T
University	University of Toronto,
Date	1990
Abstract	This thesis examines the partnership between the Wimodausis Club, an organization of upper- and middle-class women which originated in 1902,and the Earlscourt Children's Home, a Methodist institution founded in 1913 to meet the emergency needs of families fragmented by illness or the death of parent. Through a historical case study, the thesis explores the collaboration between these two organizations during three phases: From 1915 to 1947, the Wimodausis Club played a central role in shaping the policy and direction of the Earlscourt Home which provided care for approximately 1000 children. During the next phase, from 1948 to 1964, a second generation of the Wimodausis women--while less involved in the day-to-day operations--continued to play a major role in fund-raising and policy directions as Earlscourt began to employ professional workers. In the final phase from 1964 to 1971, Earlscourt was transformed into a professional children's mental health centre providing 'treatment' for emotionally disturbed children and the Wimodausis women assumed a subordinate role in its management. This study provides an analysis of how gender issues shaped the volunteer-professional partnership as Earlscourt was transformed from a voluntary women-centered religious-based institution to a publicly-funded organization which reflected a male professional ethos. It demonstrates how a real partnership between women volunteers and paid workers was more easily sustained in the pre-professional period of social work and how the members of the Wimodausis Club resisted the erosion of their influence as professionalization set in. Like the first generation of women who entered professional occupations, the primary strategies utilized by the Wimodausis included maintaining its identity as a separate women's organization and its willingness to accept a subordinate role. This thesis lends support to the view that social work has tended to trivialize the work of women volunteers and has contributed to the disparaging image of the 'Lady Bountiful'. In so doing, social work has failed to acknowledge its feminist roots and to identify the contributions and achievements made by women in the development of child welfare services.

8.

Title	Fund-raising by non-profit agencies in the health area
Author(s)	O'brecht, Michael
University	University of Ottawa,
Date	1990
Abstract	Non-profit health agencies are examined from three perspectives: their contribution to medical research by region and subject area; changes in their revenue sources and fund-raising techniques between 1982 and 1987; and, correlates of fund-raising effectiveness. Data are obtained from a survey of 1,103 health charities and foundations, interviews with the executive directors of six hospital foundations across Canada and statistics in the public domain. Results indicate that in comparison with the distribution of Federal government research grants, health agency research funding is more highly concentrated in one province, Ontario, and two subject areas, cardiovascular disease and cancer. Agencies appear to be obtaining larger proportions of their total funding from donations or business activities and smaller proportions from government grants or transfers. Large-established agencies are shifting fund-raising resources from canvassing to direct mail. Two variables, public awareness of the agency and the proportion of agency funds derived from donations, appear to be important correlates of agency effectiveness as measured by donations per fund-raising dollar. Small, positive correlations are noted between two indicators of a marketing approach and fund-raising outcome. Implications for future research are discussed.

9.

Title	Hygeia vs. panakeia; the community health centre in Canada
Author(s)	Wood, Judith E.
University	Thesis (M.A.) - Carleton University, Ottawa
Date	1986
Abstract	N/A

10.

Title	Health care and the state: community health centres in Ontario, Ottawa
Author(s)	Kelman, Vicki L.
University	(M.S.W.) - Carleton University, Ottawa.
Date	1979
Abstract	N/A

Appendix 5 – A Sample of Magazine/Newspaper Articles

1.

Title	Ontario pulls plug on health care adjustment: non-profit training and adjustment panel to be replaced by bidding process
Author(s)	Featherstone-Ruth
Mag./NewsP.	Canadian HR Reporter,
Date	1997 Je 2' v.10/11, pg 1,2.
Abstract	N/A

2.

Title	Ottawa-area community centre: Carlington Health Services. A vacant elementary school is now an inviting and eminently friendly Ottawa-area community non-profit clinic
Author(s)	Kreidie-Amanda
Mag./NewsP.	Canadian Interiors,
Date	1997 January v.34/1, pg 26-27.
Abstract	N/A

3.

Title	A feud at the Red Cross: confidential letters reveal a dispute about blood policy.
Author(s)	Jenish,-D'-Arcy; Chisholm,-Patricia
Mag./NewsP.	Maclean's; S 9
Date	1996 v.109, pg.12-14
Abstract	Debate over blood collection services, establishment of a new, publicly owned non-profit corporation, liability for tainted blood, and other issues; Canada.

4.

Title	Health coalition demands extra funds: non-profit groups say
Author(s)	N/A
Mag./NewsP.	Calgary Herald
Date	1996, July 4, pg A4
Abstract	N/A

5.

Title	Towards reducing major industrial accidents
Author(s)	N/A
Mag./NewsP.	Canadian Chemical News,
Date	1993, June, v.45/6, pg 16-18.
Abstract	The Major Industrial Accidents Council of Canada (MIACC) was established by the Federal Government in 1987 as a non-profit, neutral organization to study issues through working groups composed of specialists from stakeholder organizations. MIACC is developing a set of recommended safety practices for the full life-cycle of hazardous chemicals based on workshop studies of hydrofluoric acid and chlorine. A working group studying process safety management systems is conducting a pilot project with higher hazard potential sites operated by the Canadian Chemical Producers' Assn members. MIACC's work in emergency planning for industry was developed into a national standard with the Canadian Standards Assn. The standard sets out all the elements required in full emergency planning, including training, exercises, and auditing. MIACC is also involved in risk assessment, qualifications and training standards for emergency responders, evaluation of training, national guidelines for land use planning and control around new and existing facilities, criteria for environmental, health, and safety audits, and technology transfer.

6.

Title	Rush hour: every trip is an emergency for the Alberta Shock Trauma Air Rescue Society
Author(s)	N/A
Mag./NewsP.	Western Producer,
Date	1993, February 18, v.70/28, pg Insert 4-5
Abstract	The first Alberta Shock Trauma Air Rescue Society (STARS) was established in Calgary in 1985 for southern Alberta and the second in Edmonton in 1991 for northern areas. STARS is a non-profit society that provides rural areas with trauma care using air ambulances and volunteer medical staff. The two STARS operate under a board of directors on a $4.4m budget, about one half of which comes from fund recovery from Alberta Health, the Workmen's Compensation Board, Health and Welfare Canada, and insurance companies. The other half is raised from corporate and private donations.

7.

Title	Advantages in amalgamation for two small non-profit health care agencies (Victoria Epilepsy Assn & Victoria Parkinson's Disease Assn)
Author(s)	Martin-Caroline
Mag./NewsP.	Social Worker,
Date	1992, Winter, v.60/4, pg 213-215
Abstract	N/A